

Playing the Cancer Card: Illness, Performance and Spectatorship

Brian Lobel

Thesis submitted in fulfilment of the requirements
for the degree of Doctor of Philosophy.

Abstract

Playing the Cancer Card: Illness, Performance and Spectatorship investigates the experience of spectatorship in relation to illness, an area that has received comparatively little attention in Performance Studies. The thesis interrogates these concerns through original interviews, archival research, close textual readings of performances and performance documentation and draws on critical frameworks, primarily from performance, literary and cultural studies concerning spectatorship, illness, disability, documentation and narrative. The project analyses both my performances that exemplify being an object of spectatorship and my experiences as a spectator to the performance of illness.

Playing the Cancer Card argues that performance, through the experiences of spectatorship that it invites, works to broker the chasm between embodied experience of illness and discourses of that experience. The Introduction reviews academic literature and examines relationships between illness and models of disability. In Chapter 1, readings of work by Sontag, Spence and Baker demonstrate how individuals may strategically reject public production of, and spectatorship to, their work. Chapter 2 analyses interviews with Baker and Marcalo, demonstrating how performance can generate tensions between artists and advocacy groups when modes of spectatorship — regarding propriety and community politics — are policed. In Chapter 3, an analysis of cancer blogs elucidates how they may redress limitations imposed by traditional narrative structures around illness, forging new relationships between the ill and their spectators. Here I also consider my performances that respond to the pervasiveness of traditional narratives. Chapter 4 examines *Fun with Cancer Patients*, my practice-based research project, and argues that by addressing constructions of cancer, one may create work that productively

addresses spectators who both have and have not experienced cancer. In the Conclusion, I evaluate two of my projects that address illness tangentially, arguing that understanding ourselves as spectators and objects of spectatorship can expand discourses surrounding embodied experience, especially of illness.

Table of Contents

Acknowledgements	7
Introduction	
Chicago, 21 April 2010	10
Playing the Cancer Card	15
Illness and Disability	21
Starers and Starees	29
Liminality, Documentation and Distance	38
Brokering the Discourses	46
Structure of Thesis	52
Chapter 1: Playing More than the Cancer Card: Illness, Silence and Active inactions in the work of Jo Spence and Bobby Baker	
Jade Goody: Personifying an Age of Documentation	58
Susan Sontag: Theorising the Silence	68
Jo Spence: Embracing the Silence	76
Bobby Baker: Using the Silence	86
Jade, Gia and Rachel	99
Chapter 2: Perverts and Postergirls: Advocacy, Solo Performance and Propriety	
Bracelet and Ribbon Advocacy	103
i[2]y and the Angry Parents	111
Cancer and Policed Positivity	113
Bob Flanagan, Sheree Rose and the Implied Spectator	118
‘EPILEPSY AS ART?’ Rita Marcalo and ‘The Community’	130
Bobby Baker and the Minefield of Language	148

Chapter 3: Music is Disease: Cancer Blogs and Spectatorial Expectation

Not Your Mother's Illness Drama: Cancer Movies and Experimental Performance	169
Cancer and Precedent	187
About the Bike: Lance Armstrong and Me	194
Copping Feels in Real Time: Reading Cancer Blogs	202
Memorial Settings	213

Chapter 4: Picturing Your Life: Practice-Based Research and the Affect of Cancer

Picture Your Life After Cancer	216
Eat Me: Research, Development and the Fun with Cancer Canvases	223
Tommyknockers Tommyknockers, Knocking At My Door	238
The Guerilla Pub Quiz	251
Fun with Reflections	260

Conclusion

Illness, Wellness and Performing for 'Normals'	268
Or Else Your Friends Will Have to Do It	286
Confessions and Conclusions	289

Appendices

A: Transcription of Interview with Rita Marcalo	293
B: Transcription of Interview with Bobby Baker	300
C: Contextualising Statement for <i>Tommyknockers</i> by Sue Gessler	307
D: Contextualising Statement for <i>Guerilla Pub Quiz</i> by Sue Gessler	308
E: Contextualising Statement for <i>Guerilla Pub Quiz</i> by Anne Lanceley	309

Bibliography	310
---------------------	-----

Webography	315
-------------------	-----

List of Illustrations

Figure 1 — <i>Fun with Cancer Patients</i> website screenshot, 2010	264
Figure 2 — Online Submission, <i>Fun with Cancer Patients Canvas 1</i> , 2010	264
Figure 3 — Online Submission, <i>Fun with Cancer Patients Canvas 2</i> , 2010	265
Figure 4 — Online Submission, <i>Fun with Cancer Patients Canvas 3</i> , 2010	265
Figure 5 — Online Submission, <i>Fun with Cancer Patients Canvas 4</i> , 2010	266
Figure 6 — Online Submission, <i>Fun with Cancer Patients Canvas 5</i> , 2010	266
Figure 7 — Online Submission, <i>Fun with Cancer Patients Canvas 6</i> , 2010	267
Figure 8 — Submitted Canvas to <i>Fun with Cancer Patients Website</i> by Laura, 2010	267

Acknowledgements

I would like to acknowledge the incredible generosity of many colleagues, mentors, students and friends who have contributed to the completion of this thesis, and to my growth as researcher and performer. I would firstly like to thank the entire community at Queen Mary, University of London, who inspired me to return to higher education and provided me with the confidence and resources to explore the research contained within. I am particularly grateful to my supervisors Catherine Silverstone, Lois Weaver and Michael McKinnie for their constant support and guidance through this process. They are each incredibly inspirational thinkers and I feel humbled to have been under their supervision. I am also thankful for their encouragement and support for my QMUL Teaching Bursary, which provided the opportunity to study and teach at Queen Mary. I would also like to acknowledge my PhD cohort and my students at QM who have made valuable contributions to my research.

I would also like to acknowledge those colleagues outside of Queen Mary who have supported the work in various ways. I am grateful to have had the opportunity to present the first three central chapters at Performance Studies International (in Zagreb, Toronto and Utrecht) as well as presenting other pieces of chapters at Journeys Across Media Conference (Reading), Gobsmacked (Queen Mary), ATHE (Chicago), and Points of Exit (Maastricht). I would like to acknowledge the financial support of the Glynne Wickham Scholarship from SCUDD and the Central Research Funds of both Queen Mary and the larger University of London, who allowed me to attend these conferences and to travel to the University of Michigan in April 2010 to work with Petra Koppers, which was a turning point in my research.

I would like to thank the editorial boards at *Performance Research* and *Contemporary Theatre Review* (in particular, Dominic Johnson at *CTR*) who published papers based on Chapters 1 and 2, respectively, in Special Issues, and who were so generous and thoughtful during the peer reviewing and editing processes. I would like to acknowledge the encouragement of Bruce Henderson who was the first person to publish *BALL* in *Text and Performance Quarterly* in 2009, and who championed its inclusion in *Understanding Disability Studies and Performance Studies* (Routledge, 2010). In addition, I would like to acknowledge the support of Oberon Books and the Live Art Development Agency who, in 2012, will be publishing my scripts (*BALL & Other Funny Stories About Cancer*, Oberon Books, 2012) and video material (*Cancer Cancer Cancer Cancer Cancer*, Live Art Development Agency, 2012). I am thankful that the practical work discussed in this thesis will be publicly, and affordably, accessible.

I would like to acknowledge the venues and funding bodies who have been so supportive of my performance work, and these include the Wellcome Trust, the Jerwood Charitable Foundation, Duckie, Chelsea Theatre, Live Bait Theater, Sadler's Wells, Compass Festival of Live Art, PULSE Fringe, Forest Fringe, The Basement, decibel, the Arnold P. Gold Foundation for Humanism in Medicine, the Canadian Association for Psychosocial Oncology, and especially Performing Medicine, with whom I've taught and performed for the last three years. Working and presenting performances with medical students and faculty inside the context of Performing Medicine has allowed me to understand how critical it is to broker the dialogues between medicine and the humanities.

I must acknowledge those individuals who have been so generous as to allow me to interview them, work with them, and hear feedback from them about

my various projects and chapters, making crucial contributions to my research. Firstly, I must thank Bobby Baker, who has been such a generous presence since I moved to the UK, and Rita Marcalo. I am also incredibly grateful to Terry Dennett at the Jo Spence Memorial Archive and Simon Watney for access to his personal archive of Jo Spence's talks and correspondences. None of *Fun with Cancer Patients* would have been able to be accomplished without the *Fun with Cancer Patients* team — Christa Holka, Nako Okubo, Chipp Jansen — our medical advisors — Sue Gessler and Anne Lanceley — and the patient participants, Laura and Tansy. It is incredibly humbling to have had the opportunity to work with each of these people and to incorporate their creativity and generosity into my own project.

Finally, I would like to acknowledge and thank the support and love from my families, both biological and not, who have been kind, patient and generous beyond words in both the last 10 years since my cancer diagnosis (when all of this thinking began) and, particularly, in the last 4 years, as I've attempted to find my place in higher education, in teaching, in researching, in London, in the performance scene and in the world at large. Because being an effusive American is seen with cynicism in both the UK and in academic research, I shall simply say: Thank you.

Introduction

Chicago, 21 April 2010

I consider a status update to my Facebook profile: “Brian Lobel is at Alliance Bakery in Ukrainian Village. Beautiful day. Perfect Chicago day. I wish Grant were here.” And I instantly delete. It seems too enigmatic a status update for the 800 of my Facebook friends who never knew Grant, and too heavy for the 100 Facebook friends who did. I rewrite: “Brian Lobel is working for the day at Alliance Bakery in Uk. Village. Still stuck in Chi because of stupid Icelandic volcano and now on my last pair of clean underwear. At least it’s beautiful outside. Come keep me company.” This seems more appropriately pitched for Facebook; it’s a tenor I have learned from three years of daily status updates, constant monitoring of others’ statuses, and endless conversations with friends about whose statuses are too heavy, too personal and too emotionally needy.

The Ukrainian Village is filled with sense memories today, with nostalgia and with sadness. Five years prior to today, Grant and I used to stroll the neighbourhood with our best friend Priya, and today, Priya and I are chatting online about our seemingly-interminable sadness over Grant’s death last month. Although all three of us had left Chicago — me to London, Priya and Grant to New York City — the place remained sacred. We always knew we could not return to that time — Grant and I had long since broken up, and all three of us had matured into different people — but Grant’s death made this finality appear stricter and completely unforgiving.

The introduction above was written while on a journey to Ann Arbor, Michigan to meet with Petra Koppers and receive feedback on my practice-based research

project *Fun with Cancer Patients*, which will be discussed in Chapter 4. The trip was planned months previously, and supported by a grant from the University of London's Central Research Fund. The week was meant to be about critical engagement on issues surrounding illness and disability with Koppers, whose scholarship will be examined at length in this project. Talks were prepared, essays outlined, questions carefully worded, and professional outfits chosen. And then Grant, my first love and best friend, died in a snowmobiling accident. Suddenly, the work I had done for the nine years prior — work that tried to understand illness, mortality, and how bodies move precariously through the world — seemed to contain some very serious omissions. “Perpetual narrative wreckage,” as Arthur Frank writes in *The Wounded Storyteller*, may be “endemic to postmodern times”, but as I attempted to craft meaning from the world around me, I was unable to realise that my experience might be linked to larger critical discussions.¹

Because of the emotional state I was in, when I arrived in Ann Arbor, strict academic engagement gave way to personal meandering encouraged, surprisingly to me, by Koppers herself, a self-described earth mother who dresses comfortably, speaks casually and engages with theory on a deeply personal, even sensual, level. Instead of thinking about critical theory around illness and somatics, I began to think about where I was in 2010, as opposed to the last time I had been in Ann Arbor. I began to think about *my* illness, the cancer I had as an undergraduate at the University of Michigan and the sights and sounds that were associated with that time. Ann Arbor became a smorgasbord of sense memories of my personal history. The buildings of the University of Michigan sang with stories — cancer diagnosis at the University

¹ Arthur W. Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: The University of Chicago Press, 1995), p. 68.

Health Services on Halloween, 2001, a head shaving party on 8 November 2001, the coming out with illness to my professors after I returned to classes in 2002, the premiere of my performance *BALL* in 2003, awkwardly and uncomfortably revealing my post-cancer body to lovers from 2002-2004. The sense memories of that place were undeniable.

As soon as Ann Arbor opened itself to memories both in mind and body, the stories of the place began to ring out from my non-cancer-related and more contemporary past. I passed the former home of my friend Gia, now living with cancer, and of my friend Katie, whose mom recently passed away after a lengthy battle with lung cancer. I drank coffee at Amer's deli, where I worked for six shifts before I was diagnosed with cancer. I learned that Carla, my manager at the time, had not died of cancer — as we thought she had — but was alive and working at the Department of Motor Vehicles in Miami, Florida. The entirety of Ann Arbor rang with the label of the University of Michigan and reminded me of how I was labelled on the program of Grant's funeral: "Brian Lobel: University of Michigan Friend". While I never knew Grant while at the University of Michigan, it must have seemed a more appropriate label than "Sometimes Boyfriend" or "On-and-off Best Friends". It was funny to me how that label could retrospectively make Ann Arbor a place where I felt Grant, even though we had never been there together.

As evidenced here, the writing of this PhD thesis has been a deeply personal and reflective process — an attempt to make sense of, collate, and theorise about the past ten years of my lived experience and performance making, as well as the larger performance and critical contexts in which I have been researching and responding. I hope to demonstrate, throughout this thesis, that critical reflections on practice, as well as experience, are essential to

the intellectual work here, which considers modes of spectatorship and the ever-changing configurations between audience, performer and spectator. I have developed my methodology with close reference to Petra Kuppers' *Scar of Visibility* (2007) as well as Roland Barthes' *Camera Lucida* (1981), Peggy Phelan's *Mourning Sex* (1997), Jackie Stacy's *Teratologies* (1997) and Adrian Heathfield's 'Walking Out of Life' (2009), who each embed autobiography as an essential and deeply commingled part of the territory of their exploration. In particular, I draw my approach from Kuppers who writes eloquently about her adoption and adaptation of current phenomenological approaches to research:

[P]henomenological approaches often lay themselves open to the critique of being unable to account for systemic formations, and to formulate a politics of subjectivity. In my work, I weave together a phenomenological emphasis on experience and embodied action with a trajectory toward deconstructivist unknowability, and I situate this nexus within a political change agenda.²

Unlike Kuppers (and perhaps because of my years working inside medical schools and dealing with their 'objective' measurements) I was originally less comfortable with approaching unknowability, but always embraced Kuppers' emphasis on experience and a politics of subjectivity. I embrace them in hopes of being part of a dialogue between medical and performance studies discourses which, in order to bridge the gap in methodologies, requires medical discourses to embrace (at least as much as they can) an understanding of subjectivity.

My approach is also clearly inspired and informed by the myriad of solo performers I have encountered on my journey as student, researcher and performer, and who have used their performance texts to speak to multiple audiences across disciplines. It is not only the theory that has been derived

² Petra Kuppers, *The Scar of Visibility: Medical Performances and Contemporary Art* (Minneapolis and London: University of Minnesota Press, 2007), p. 2.

from these performances — about feminism, the body, race, class, disability — but watching the boldness and fearlessness of these artists (Peggy Shaw, Annie Sprinkle, Robin Deacon to name but a few), has provided opportunities for a further interrogation of my own experiences as essential to understanding larger critical arguments. This past year, while Peggy Shaw guest lectured at King’s College School of Medicine (where I convene the Performing Medicine module), I witnessed 12 medical students hanging on her every word, and — during a class that was meant to be on autobiographical writing — learning about the experience of having a stroke in an incredibly visceral and affective manner. Jill Dolan has previously described Shaw’s performance work as filled with intersubjective moments in which audiences experience utopia, even momentarily; to watch such an affective connection being used in a half-day workshop was unexpected and incredibly informative about the possibilities of such a connection.³ Inspired by these performances and encouraged by such personal and emotive takes on research and theory, the writing of this thesis aims to add an impassioned and charged voice to current dialogues about illness and spectatorship. It argues that such an affective connection can be used to open up previously rigid discourses (around medicine, and even disability) and add critical perspectives to how embodied experience is currently discussed.

At the beginning of the thesis, it is incumbent upon me to clarify the tone and writing style that I will be employing to make the above arguments in this thesis. Formally, the style and tone take inspiration from the aforementioned performers and theorists who imbed personal history and reflection at the core of their theory, reiterating and emphasising the process of this PhD — a

³ Jill Dolan, *Utopia in Performance: Finding Hope at the Theatre* (Ann Arbor: The University of Michigan Press, 2005), p. 54.

reflection on 10 years of cancer-related practice and contextualising that work inside a broader investigation into illness and performance — which will inform its structure as well as its framing. Because the theory and case studies have been lead, first and foremost, by life experience, accidents and events, it feels essential to revisit the personal in hopes of clarifying what may seem at times, a random ordering of reflection and theoretical engagement. Although I have attempted to be as linear and well-signposted as possible, it is the slippage into chaos or disorder which remains a central guiding force. In this way, this thesis enacts, what Reason calls “an archive of detritus” not unlike the stage floor at the end of an early-career Forced Entertainment piece.⁴ This archive of detritus (discussed in further detail in this Introduction) upends the presumptions of neutral detachment and objectivity to consistently reemphasise a creator’s specific cultural, intellectual, and perhaps even medical, position to open up further possibilities for debate and discussion. In this way, I hope to demonstrate that narrative frames which I’ve given to the chapters of this PhD are meant less as tricks to inspire emotion or pathos, but rather as earnest statements about the origin of the following theory, thus allowing the reader to gain a bit more access into how and why the work is argued as it appears.

Playing the Cancer Card

Playing the Cancer Card: Illness, Performance and Spectatorship investigates the experience of spectatorship in relation to illness from multiple perspectives. The thesis argues that projects surrounding illness address issues of spectatorship, narrative and identity in a manner that is multivalenced and currently under-examined in theatre and performance studies. This thesis

⁴ Matthew Reason, *Documentation, Disappearance and the Representation of Live Performance* (Basingstoke: Palgrave Macmillan, 2009), p. 54.

investigates how people with illness negotiate these various modes of spectatorship and what this might tell us about the experience of illness which is so common yet under-discussed both in critical theory and contemporary Western society. The method for interrogating people's understanding of spectatorship will be done through close readings of performances and performance documentation, examination of archival materials and interviews with performance makers about their negotiations and processes. I shall also reflect critically on my own body of practice from 2003-2010 which addressed these similar concerns. There is a significant and rich body of work on spectatorship as it relates to disability studies, particularly by Rosemarie Garland-Thomson and Petra Koppers, but even though disability studies often includes illness, this relationship between illness and disability has remained unclear in research, demanding clarification and exploration. Because of its status as a liminal state, a person's ontological state during an illness — as opposed to disability which is not considered liminal by virtue of the social model of disability taken as a given by most scholarship — has a unique relationship with spectatorship. This relationship involves a performance of health, survival and bodily security which is different than that which is dealt with by people with disability.

This thesis is primarily concerned with modes of spectatorship in relation to the experience of cancer. Most of the projects I will be considering in each chapter look primarily at this experience which is heavily and historically loaded with meaning. Some have argued, as Jackie Stacey has, that the term cancer is meaningless, “including so many different diseases and treatments that any generalisations are rendered redundant”⁵ and this may be, biologically

⁵ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (London and New York: Routledge, 1997), p. 30.

speaking, true. Siddhartha Mukherjee's recent 'biography of cancer' *The Emperor of All Maladies*, however, charts the "deep cultural and political themes that run through the various incarnations of cancer to justify a unifying narrative."⁶ Mukherjee's history of cancer research demonstrate that this unification is the result of a lengthy and conscious history. In the 1950s and 1960s, especially in the United States, both oncology researchers and cancer fundraisers made a strategic decision to lump all all cancers together in hopes of centralising and invigorating the cancer 'cause'.⁷ Today, the generalising around the word cancer continues to pervade public consciousness. Because of the way that cancer has been generalised, I will argue that the expectations of spectatorship from both the perspective of cancer patients and non-cancer patients remains similar (if not identical) across cancer types. By exposing this amalgamation of different cancer experiences as a given, I hope to demonstrate how this amalgamation affects the discourse as a whole. Doing this will allow me to link the experiences of, for instance, Jo Spence's breast cancer, Paul Nicholls' bowel cancer, and my own experience with testicular cancer. Acknowledging the particularities of individual experience, this approach recognises the potency of the word cancer to affect powerfully (if not wholly) an individual's view of their own body, and the expectations placed upon that body (now defined as a body with cancer) by others.

As with my linkages between various cancers, the approach in this thesis brings together a consideration of a number of different performance practices. This is an approach exemplified by many of the theorists upon whose work I am drawing, including Koppers and James Thompson. Both Koppers and

⁶ Siddhartha Mukherjee, *The Emperor of All Maladies* (London: Fourth Estate, 2011), p. xvii.

⁷ Mukherjee, p. 155.

Thompson, in their research, identify the practice of looking at various forms of artistic production as central to studying performance affect. Thompson defines affect as that which “refers to emotional, often automatic, embodied responses that occur in relation to something else — be it object of observation, recall of a memory or practical activity” and I will employ Thompson’s definition to examine how performance — in its various forms — is, or can be, responsible for such embodied responses.⁸ My research will use Thompson’s specific configuration of affect, as something which is relational, to demonstrate how various types of performance work can trigger not only automatic, embodied responses, but also a desire to engage with such automatic responses towards critical ends.

Regarding the kind of work which may cause such affects, Koppers draws distinctions between professional performance work and incidental performance taking place in non-traditional spaces. She recognises, however, that in both realms, any activity (be it performance, protest or everyday business) can have a significant impact on spectators and are, essentially, responsible for similar processes.⁹ Thompson, in his introduction to *Performance Affects*, also argues for such a non-distinction:

The primary use of ‘performance’ in this book is an inclusive term for all those artistic practices that include the participation of groups and individuals as they present themselves to others. This might be in dance, music, poetry recital or theatre and could take place in a small room or in a huge arena — and, vitally, might be done by people who are not usually permitted to call themselves artists. Performance is used to illustrate the widest possible set of artistic forms and also avoid the assumption that a staged event is one that only uses the spoken word or some linear narrative structure.¹⁰

⁸ James Thompson, *Performance Affects: Applied Theatre and the End of Effect* (Basingstoke: Palgrave Macmillan, 2009), p. 119.

⁹ Koppers, p. 7.

¹⁰ Thompson, p. 7.

In drawing on Koppers' and Thompson's approaches, I hope to provide context for the, at times, wildly divergent forms of artistic and social material that I consider in close proximity to one another.

This thesis takes, as its central object of research, performance affect, and is significantly less concerned with analysing or providing critical readings of performances themselves. Given Thompson's and Koppers' incredibly broad definition of performance practice — which I will argue are the most useful frames when considering performance work on illness and disability — it is through affect that these performances can be most critically contextualised into a broader conversation. This will be most clearly exemplified in Chapter 2 and with the work of Rita Marcalo, for whom the affect of *Involuntary Dances* (the media controversy, online responses to her work and her own reflection) became the most crucial and important aspect of the performance itself. Additionally, as I hope to demonstrate in Chapter 4 with *Fun with Cancer Patients*, an overwhelming majority of work created with or about illness remains myopically focused on effect, so much so that such effects can become prescribed and disempowering. A focus on performance affect, in this regard, opens up possibilities for academics studying performance and its effects/ affects on communities of people with illness, but may also open up possibilities for people with illness to reexamine how they contextualise themselves inside broader conversations. Finally, the focus on affect, as opposed to strict adherence or investment in a give form of performance, has been essential to my own creative work made in response to illness, and so it is from this perspective that I feel most confident in examining the projects contained within, and the perspective that I believe gives the most insightful exploration of the material.

Given that my own work has taken the form of installation, monologue, cabaret and performance publication, recognising this movement between modes feels necessary to understanding the affects that a body or oeuvre of work may be trying to impart. This understanding also locates this thesis inside the context in which I've been living and creating, defining the scope of this project on performance projects and actions primarily in the past twenty years in Britain and America. Where this thesis looks at illnesses other than cancer or experience which may be defined as disability (a distinction I will clarify later in this introduction), it is the affect caused by these illnesses and disabilities that I am studying, rather than the specifics of the illnesses or disabilities themselves. I use these examples (particularly in Chapter 2) to illuminate perspectives on spectatorship and affect as they relate to personal embodied experience, and recognise that what cancer and these illnesses and disabilities have in common (if nothing biologically speaking) is the ability to, as Carrie Sandahl and Philip Auslander describe, "cause a commotion" in public spaces.¹¹ This commotion that they describe may reveal itself in different manners, depending on the specific illness, its physical appearance (especially important when considering distinctions between disabilities/illnesses which are apparent to all spectators as opposed to those which may be considered 'invisible' illnesses or disabilities) and the sociopolitical history associated with such an illness (Kaposi's sarcoma — a skin cancer associated with HIV/AIDS — causing a different commotion that the hairlessness associated with chemotherapy treating other cancers). This thesis will demonstrate that it is not only the physical attributes of an illness or disability which cause commotions, but also the learned histories associated with that illness or disability, as inaccurate or accurate as those may be.

¹¹ Carrie Sandahl and Philip Auslander, eds., *Bodies in Commotion: Disability & Performance* (Ann Arbor: The University of Michigan Press, 2005), p.2.

Illness and Disability

The experience of illness has been written about extensively in fiction and non-fiction (the essays of Virginia Woolf and E. M. Cioran for example) and, as Susan Sontag writes in *Illness and Its Metaphors*, has been predominantly used as a symbol for personal, national or metaphysical failings.¹² Critical studies surrounding illness, however, have been predominantly considered under the umbrella of disability studies which, I will demonstrate, may not be entirely helpful or useful for the particularities of experiences defined as illnesses.

Although there is much overlap, the distinction between illness and disability maintains significant ontological differences. The conflating of these two terms — and their respective ideologies — is no more obvious than in Frank's *The Wounded Storyteller*, which problematically discusses disease, illness, chronic illness and disability without distinction. A passionate voice for understanding how people with illness or disability *may* create narrative out of their experience and communicate their experience to the outside world, Frank — a regularly-quoted source on the subject of illness and narrative — employs a tone of certainty around experience which, in some ways, denies individual experience.

Frank writes:

[D]isease itself is a loss of predictability, and it causes further losses: incontinence, shortness of breath or memory, tremors or seizures, and all the other 'failures' of the sick body. Some ill people adapt to these contingencies easily; others experience a crisis of control. Illness is about learning to live with lost control.¹³

While creating some room for alternative experience, Frank's dichotomy of 'adapt to these contingencies easily' or experiencing a 'crisis of control' seems not only to predetermine the reactions of those with illness, but also separates

¹² Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Anchor Books, 1990), p. 43 and 49.

¹³ Frank, p. 30.

them out as a distinct population that is functioning differently than the rest of the non-ill world when, in reality, all people experience illness at one point or another.

The essentialism in Frank's discussion (reiterated by the inclusion of a number of quotes throughout his writing about what people with illness *must* do to recoup their sense of being) remains closely aligned with medical models of understanding the body — when it is sick and worthy of attention versus when it is not sick and not needing attention.¹⁴ Frank's writing feels quite intimately rendered and passionate in its usage as a text to assist people with illness to create narrative wholeness out of the disjuncture of illness similar to that illness that he himself experienced. The work, however, and perhaps despite its good intentions, employs a somewhat essentialist tone when it categorises potential illness experiences and narratives into distinct modes such as The Quest Narrative, The Restitution Narrative or The Chaos Narrative.¹⁵ His writing generally sits in stark contrast to contemporary critical disability discourses with regards to its treatment of the body and performative understandings of embodied experience. Frank writes, for instance, that:

In modernist thought people are well *or* sick. Sickness and wellness shift definitively as to which is foreground and which is background at any given moment. In the remission society the foreground and background of sickness and health constantly shade into each other.¹⁶

Here Frank's certainty about his own embodied experience makes him realise that health and illness shade into each other, but he takes this as a unique perspective on illness, as opposed to general experience, otherwise (and

¹⁴ Frank, p. 56.

¹⁵ Frank, p. 75.

¹⁶ Frank, p. 9.

elsewhere almost exclusively) reaffirming the modernist discourses he assails in this short passage.

In contrast to Frank's approach, disability studies, has understood bodies to be less about bodily certainty and more about a range of experiences which may all be considered together. As Margrit Shildrick writes about her usage of the spelling dis/abled, the term

connotes neither the one nor the other, but expresses instead a refusal to fall in with the normative pattern of binary structure, whether of material embodiment as such, or of the diverse attributes said to adhere to particular bodies.¹⁷

The stroke in dis/abled in many ways responds to Frank's separation of illness from 'normal' experience by challenging the exceptionalism which he elsewhere espouses for this time. Shildrick's central argument posits that the usage of disabled and disability can be applied to recognising a multitude of embodied experiences.

Disability studies scholarship usefully questions the relational quality of disabled identities while rejecting ideas of 'truth' which are so pervasive throughout Frank's writing. This denial, Sandahl and Auslander write, "is not meant to minimise or deny the very real experience of disability and impairment. Instead, it allows people with disabilities to intercede in the meaning-making process".¹⁸ This meaning-making process, led by people with disabilities themselves, represents a political and activist shift towards the understanding of disability through a social, as opposed to medical model, of disability. Lennard Davis, one of the preeminent voices on disability studies, neatly charts the

¹⁷ Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (Basingstoke: Palgrave Macmillan, 2009), p. 174.

¹⁸ Sandahl and Auslander, p. 14.

distinctions between the social (or civil rights) model of disability, which developed in the late 70s in opposition to the medical or charity model:

For people with disabilities the civil rights model was seen as more progressive and better than the earlier charity and medical models. In the earlier versions, people with disabilities were seen variously as poor, destitute creatures in need of the help of the church or as helpless victims of disease in need of correction offered by modern medical procedures. The civil rights model, based on the struggles of African Americans in the United States, seemed to offer a better paradigm. Not plagued by God nor beset by disease, people with disabilities were seen as minority citizens deprived of their rights by a dominant ableist majority.¹⁹

The social model of disability, therefore, becomes a political distinction which frames embodied experience in a relational and open manner and, most importantly, limits the impact of medical distinctions in the defining of disabled identities, which was much the case in Frank's writing quoted above. Sandahl and Auslander write that to "think of disability not as a physical condition but as a way of interacting with a world that is frequently inhospitable is to think of disability in performative terms — as something one does rather than something one is" thus defining disability in similar terms to Judith Butler and gender performativity which has framed significant contemporary conversations about identity.²⁰ Thought of in relation to Butler's description of gender as a "corporeal style" in *Gender Trouble*, Sandahl and Auslander's work — amongst others in disability studies — adds a particular dimension to the theory of performativity Butler describes by both recognising the physical and legal realities which define disabled identities while simultaneously recognising these identities as constitutive of an 'act' which is both intentional and performative.²¹

¹⁹ Lennard J. Davis, *Bending over Backwards: Disability, Dismodernism & Other Difficult Positions* (New York and London: New York University Press), p. 12.

²⁰ Sandahl and Auslander, p. 10.

²¹ Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (London and New York: Routledge), p. 177.

One of the goals of this research is to recoup the experience of illness as part of wider disability narratives, while claiming very clearly illness's relationship with the term disability, and the way that illness may add different textures to scholarship in disability studies, especially in relationship to medical models and social models of disability. As Koppers writes, "disabled communities have questioned the inclusion of some of these people, including people with mental health issues or learning disabilities, or 'illnesses' such as cancer, in their ranks".²² While the social model of disability would seemingly embrace those with illness — and finds them disabled by society's views that one must be healthy, productive and look a certain way — the dis-ease with medical models of disability seemingly distances those with illness in problematic ways. It does so especially for those who do not define as disabled nor wish their illness as part of a normative experience.

The discomfort of disability scholarship in recognising essentialised normative vs. non-normative experience may be in direct contrast to people with cancer who prefer not to be part of the disability community or even the disability conversation. Understanding Davis' rubric for the employment of medical or social models of disability, it becomes clear how illness sits uncomfortably next to current disability discourses, especially with regard to his statement, above, about charity. Although charities do exist for people with disabilities, their existence is far less common than those serving people with cancer or finding cures for various cancers. Because the disability movement has succeeded in pushing people away from charity models, cancer charities (Macmillan Cancer Support, Cancer Research UK, Movember, the Susan G.

²² Petra Koppers, *Disability and Contemporary Performance: Bodies on Edge* (New York and London: Routledge, 2003), p. 7.

Komen Foundation, for example) remain unchallenged and are still not considered, on the whole, patronising or oppressive.

When producing my own work around cancer, I am frequently asked “Where is the money going to?” as if a show about cancer is taken for granted to be charity. Even if disability studies or disability activism have embraced illnesses such as cancer in their remit, I’d suggest that their embrace is not required. Instead, I would argue that the rationale for so many cancer charities is that people with cancer are still considered and may consider themselves — as disability activists fought so hard against — the “helpless victims of disease in need of correction offered by modern medical procedures” that Davis describes above. This is not to say that there is not significant activism around cancer — the February 2012 controversy around Susan G. Komen’s de-funding of Planned Parenthood clinics in the USA is one recent example — but most of this activism remains geared towards research and treatment, as opposed to an understanding that bodies function differently at different times.²³ They do not usually, as Mukherjee suggests, recognise that cancer is simply a “distorted version of our normal selves” and such a thought may remain highly controversial.²⁴ Until this changes, illnesses such as cancer will not fit directly next to current disability studies scholarship which may have a strong activist agenda particularly in relation to the medical model which it generally rejects. Although this imperfect placement alongside each other may throw up useful distinctions, there seems not to be a broad consideration of these distinctions at

²³ Luiseta Lopez Torregrosa, ‘A Skirmish Over Women’s Health Gets Political’, *The New York Times*, 7 February 2012, <<http://www.nytimes.com/2012/02/08/us/08iht-letter08.html>> [accessed 8 February 2012].

²⁴ Mukherjee, p. 39.

the current time, with most scholarship preferring to include illnesses such as cancer inside critical research on disability.

While I do not believe scholarship's bias against medical models of disability represents a "radical socio-political perspective" as has been argued by Colin Barnes and Geof Mercer, the current favouring of social models by disability activists may demonstrate discomfort around 'cure' and its effect on identity and social identification.²⁵ This discomfort may be in part because of the privilege that can come along with 'cure', as written about by Davis ("Just as people can slip into disability in the blink of an eye or the swerve of a heel, so too can people be cured") or the ability for people with illness to pass as not disabled.²⁶ The discomfort may also come from the flux of illness, or at least the language that is used to describe it: if one is in a stage of illness, they are, by the nature of the word 'stage', in process of getting out, trying to get out, or moving in between a given space or spaces.

Johnson Cheu describes 'cure' as "the very heart of the tension between disability as medical impairment and disability as cultural identity" and successfully links the tension between how medical treatment is enacted upon bodies.²⁷ "If disability is simply understood as a bodily impairment that is medically curable", Cheu writes

then disability as culture is nonexistent. However, if disability exists as a culture, if a disabled body is to be seen as a representational system upon which experiences of disability in society are projected, then medical cure of the disabled body must be understood as a construction.²⁸

²⁵ Colin Barnes and Geof Mercer, eds., *Exploring the Divide: Illness and Disability* (Leeds: The Disability Press, 1996), p. 7.

²⁶ Davis, p. 25.

²⁷ Johnson Cheu, 'Performing Disability, Problematizing Cure' in Sandahl and Auslander, p. 139.

²⁸ Cheu in Sandahl and Auslander, p. 139

With all of the focus of cancer being about Race for the Cure, or Cancer Research (presumably to find a cure), these two distinct perspectives feel at continual odds and justify, perhaps, a separation of cancer from disability studies and disabled culture. This is not to say that there are not people who are disabled by their cancer, and for whom this disability becomes a salient identity, but popular discourse around cancer tends not to reflect this.

For those with cancer, and particularly those immediately diagnosed with cancer, based on my personal experience and years of speaking with new patients as a performer and through personal connections, very rarely do they find themselves embracing wholeheartedly the notion that bodies are different, always exceptional, or that the idea of a medical cure for their cancer might be conceived of as a construction. Instead, cancer patients are more often embraced by Parson's "sick role" which very much befits a medical understanding of cancer and its treatment. The role, which Frank elucidates in *The Wounded Storyteller*, calls upon the person with illness to 1) not be blamed for their condition,²⁹ 2) be exempt from normal responsibilities and 3) submit fully to the treatment of doctors.³⁰ While such a role was quite easy for me to fulfil when diagnosed at age 20 (I was too young for lifestyle choices to affect me, I moved home to live with my parents, I submitted to a clinically-proven course of medicine), I now realise how quickly and extensively I was affected by the medical model of disability, dictating that my disablement (in this case, malignancies causing harm in any number of ways) be repaired expeditiously. While the medicalised goals of eradicating an impairment (walking again for wheelchair users or hearing, as it is very controversially suggested to people in

²⁹ Whether or not this holds true in the age of anti-smoking campaigns and mesothelioma lawsuits is debatable.

³⁰ Parson's "sick role" developed in the early 1950s discussed in Frank, p.81.

the Deaf community) are offensive and prove to prioritise one type of body normativity over others for disabled people, these goals are more-than-likely exactly what a person with cancer is responding to and aiming for. I will evidence this distinction in the coming chapters, particularly through the examples of Jo Spence and Audre Lorde in Chapter 1 and through examining their reactions (and resistances) to their diagnoses and treatments.

There is nothing inherently wrong with a goal of cure, particularly when non-cure can quickly bring about death. Rather, it is the deployment of a 'cure' framework inside cancer treatment (and fundraising) that causes illness to sit awkwardly alongside existing disability studies scholarship. The most exciting and productive scholarship recognises the term disabled, much like queer, as a strategy for understanding and challenging normativity, as opposed to an essential category. As Eve Kosofsky Sedgwick has suggested that "'queer', can refer to: the open mesh of possibilities, gaps, overlaps, dissonances and resonances, lapses and excesses of meaning when the constituent elements of anyone's gender, of anyone's sexuality aren't made (or *can't be* made) to signify monolithically", a similar and powerful scholarship (like that by Koppers and Shildrick) uses disability to describe its own open mesh of possibilities.³¹ This realm of possibilities allows disability to be recognised more as a strategic worldview and less as being constituted by a rigid set of distinguishing features.

Starers and Starees

Playing the Cancer Card is interested in how the objects of spectatorship — or, to use Rosemarie Garland-Thomson's term, the staree — are responding to

³¹ Eve Kosofsky Sedgwick, *Tendencies* (Durham: Duke University Press, 1993), pg. 8-9.

feelings of being watched by audiences — or starers — who can be configured as either audiences to their performance, visitors to their hospital bedroom with them or at the other end of a digital exchange.³² Most of the work on staring is written in response to people with physical disabilities and often employs Erving Goffman's seminal work in *The Presentation of Self in Everyday Life* to demonstrate how viewers use 'sign-vehicles' to understand people's identities, and how people who are being watched have a good understanding about how to best represent themselves to others.³³ Goffman's understanding — as Sandahl and Auslander discuss in relation to disability —

emphasises that identity does not simply reside in individuals but is the product of social interactions among individuals. This perspective is congruent with the view of disability as something that is not an intrinsic characteristic of certain bodies but a construct produced through the interaction of those bodies with socially based norms that frame the way those bodies are generally perceived.³⁴

Here, Sandahl and Auslander relate Goffman's theory to explicitly highlight the experience of disability according to a social model, demonstrating that not only must that model be applied by oneself, but the model must also be recognised and in dialogue with others who may or may not be disabled. As Sandahl and Auslander write, "Visibly disabled people know that when out in public, they must respond to these questioning stares" in part as a visible 'other', but also as part of the relational experience of identity establishment.³⁵

Playing the Cancer argues that the presence of the cancer patient in public space causes a similar, if slightly-differently-inflected, commotion; the

³² Rosemarie Garland-Thomson, *Staring: How we Look* (Oxford: Oxford University Press, 2006), p. 2.

³³ Erving Goffman, *The Presentation of Self in Everyday Life* (New York: Anchor Books, 1959), p. 13.

³⁴ Sandahl and Auslander, p.215.

³⁵ Sandahl and Auslander., p.130.

heaviness of various cancer signifiers insist that cancer patients respond, as above, to questioning stares. The stares may be different than those faced by people with visible disabilities, questions like “What happened to you?” as the stare of those watching the cancer patient may have similarly invasive questions attached to them. Questions like “What are you sick with?” “Are you going to live?” “What kind of treatment do you receive?” were all questions I received personally. When not faced with spoken questions, I was still well aware that I looked different than most people, or, as Jackie Stacey describes about herself in *Teratologies*, “I am aware I am a sight”³⁶ This was similarly true for Audre Lorde who, upon seeing a close friend remarked,

the look in her eyes when she saw me made me really angry, but it also made me realise how much weight I’ve lost in the past year and how bad my color’s been since I came home from Australia.³⁷

With such potent stares, it is clear that cancer patients — or at least those with visible outward symptoms such as hair loss or weight loss — possess their own meanings when appearing in public space. And, much like people with visible disabilities as Sandahl and Auslander describe, they are generally implored to respond in some way.

What Garland-Thomson’s recent work in *Staring: How We Look* adds most particularly to this conversation of spectatorship is the explicitly reciprocal nature of being both starrer and staree. The intense “visual engagement” of a stare, Garland-Thomson writes,

creates a circuit of communication and meaning-making. Staring bespeaks involvement, and being stared at demands a response. A staring encounter is a dynamic struggle — starers inquire,

³⁶ Stacey, p. 139.

³⁷ Audre Lorde, *The Audre Lorde Compendium: Essays, Speeches and Journals*, (Pandora: London, 1996), p. 287.

starees lock eyes or flee, and starers advance or retreat: one moves forward and the other moves back.³⁸

By recognising the give and take of the stare, Garland-Thomson opens up the potential for pleasure and equity (or if not absolute equity, some sort of parity) in the relationship.³⁹ The existence of pleasure and equality marks quite a progressive step forward from the pervasive rubric of ‘the gaze’, which sees the relationship between starrer and staree as inherently oppressive. This is particularly true in relation to ‘the gaze’ as described by Laura Mulvey, because of the inability of the staree (in this case, as a Classic Hollywood film actress) to look back. In her seminal essay ‘Visual Pleasure and Narrative Cinema’ Mulvey demonstrates how scopophilia, or pleasurable looking, drawn from psychoanalysis, applies to film spectatorship of Hollywood classics, and — as classic Hollywood cinema was crafted — that the power, or active role, was held exclusively by male audiences, and that women were invited to have their gaze relayed through that male subjectivity. She writes:

In a world ordered by sexual imbalance, pleasure in looking has been split between active/male and passive/female. The determining male gaze projects its phantasy on to the female form which is styled accordingly. In their traditional exhibitionist role women are simultaneously looked at and displayed, with their appearance coded for strong visual and erotic impact so that they can be said to connote to-be-looked-at-ness.⁴⁰

Extending the imbalance of power she describes as existing between men and women to other agent and target groups, Garland-Thomson identifies how the ‘gaze’ now is — rightly or wrongly — applied more broadly with the recognition that Others are put on display and looked at. Garland-Thomson writes:

³⁸ Garland-Thomson, p. 2-3.

³⁹ Garland-Thomson, p. 10.

⁴⁰ Laura Mulvey, ‘Visual Pleasure and Narrative Cinema’, *Screen*, Volume 16, No. 3, 1975, p. 9.

The male gaze produces females subjects; the normative stare constructs the disabled. While both are forms of visual marking, gazing trades on a sexual register and staring traffics in medical discourse. Both visual exchanges prompt narrative. Gazing says, "You are mine." Staring says, "What is wrong with you?" Gazers become men by looking at women, and starers become doctors by visually probing people with disabilities.⁴¹

Even if women or men with disabilities create a different kind of erotic impact on the viewer, their appearance is often coded for strong visual impact, and the starting point of various narratives as I've described above. It potentially raises issues of pity, of fetishistic desire, or of, as Harlan Hahn writes, existential or aesthetic anxiety around difference.⁴²

While Mulvey's frame may be applied directly to how non-disabled people may view disabled people who are unable to look back, Garland-Thomson's research addresses how those with disabilities look back with strength and with consciously crafted strategies, such as those described by Goffman whose *Presentation of Self in Everyday Life* was simply applied to those working in service industries.⁴³ The central aim of her study, Garland-Thomson writes, is to unsettle "common understandings that staring is rudeness, voyeurism, or surveillance or that starers are perpetrators and starees victims. Instead, this vivisection lays bare staring's generative potential."⁴⁴ Through interviews with people who are often the subject of stares, and asking them how they respond to the inquiry, Garland-Thomson demonstrates that people with disabilities needn't be the unresponsive victims of the gaze that used to be portrayed in Hollywood film. A strong argument

⁴¹ Garland-Thomson, p.32.

⁴² Jim Ferris on Hahn in 'Aesthetic Distance & the Fiction of Disability' in Sandhal and Auslander, p.42-43.

⁴³ Goffman, p. 110.

⁴⁴ Garland-Thomson, p. 10.

could be made that Garland-Thomson lets “starers” (or what is conceived of as those with normative bodies) off the hook a bit too much throughout her analysis. By choosing a sample of case studies throughout that reflect strong, politicised individuals (artists and non-artists alike) such as Alison Lapper, Matuschka or Jo Spence, each of whom have crafted strategies for staring back, the reader may forget those who are not empowered by being the object of a stare.⁴⁵ This recognition, however, may be outside the scope of Garland-Thomson’s study, which uses the starrer/staree relationship to find unexpected moments of empowerment and inspiration.

Garland-Thomson’s study looks at non-artists and their relationship to the stare. In this thesis, I will extend her work by applying her methodology to artists and their relationship to the stare in order to locate the experience of illness within the existing discourse in performance studies on spectatorship and the gaze. As part of *Playing the Cancer Card*, I will also consider how the exclusion of a literal stare (as may be the case with ‘invisible illnesses’ or projects with virtual audiences) may affect audience reception. A final part of Garland-Thomson’s argument that I will develop will be the relationship of staring to *action*, and the *actions* of spectators. Garland-Thomson relates her work to Sontag’s *On Photography* and Sontag’s fear that horrific images inhibit action (which I will consider in Chapter 1). I will deploy Garland-Thomson’s work in relation to performance studies’ concerns about audience and alterity, incorporating Helena Grehan’s recent work on the ethics of spectatorship, which draws heavily on Levinas’ ‘Useless Suffering’.⁴⁶ By doing so, I intend to

⁴⁵ Garland-Thomson, p. 151.

⁴⁶ Helena Grehan, *Performance, Ethics and Spectatorship in a Global Age* (Basingstoke: Palgrave Macmillan, 2009) and Emmanuel Levinas, ‘Useless Suffering,’ trans. Richard A. Cohen, *The Provocation of Levinas: Rethinking the Other*, Robert Bernasconi and David Wood, eds. (London: Routledge, 1988).

demonstrate not only that the performer/audience or starrer/staree relationship may contain the potential for pleasure, but that it may have potential for political, social or medical efficacy in a number of ways.

In 'Useless Suffering', Emmanuel Levinas considers the relationship between the individual who suffers and the moral and political imperative placed upon the Other, describing the nature of inter-human relations as containing a specific recourse, for individuals, to receive help from others.⁴⁷ This recourse and mention of responsibility, I will argue, may illuminate the relationship described between the starrer and the staree. I have tried not to conflate the terms staree with disabled or person with illness (especially in relation to the work of Shildrick and Garland-Thomson) but in order to consider Levinas' frame — which I will demonstrate uses 'sufferer' as a general state and not specific or separate group of people — the conflation is momentarily employed. Levinas' description of this interaction using the concept of the 'inter-human' has recently been applied in a performance context by Helena Grehan writing on an ethics of spectatorship, in which Levinas' subject, inter-human and Other correlate directly to ideas of performer and audience.⁴⁸ Grehan's proposed ethics of spectatorship and reading of Levinas may help inform an understanding of witness and the relationship between performer and spectator. I will complicate this relationship further by employing Garland-Thomson's redefinition of staring in hopes of demonstrating a more ambiguous inter-human territory.

Levinas argues against theorists who rejected witness-able representations of suffering like Adorno, who had written that the "the so-called

⁴⁷ Levinas, p. 165.

⁴⁸ Grehan, p. 6.

artistic rendering of the sheer physical pain of people beaten to the ground with rifle butts contains, however remotely, the power to elicit enjoyment out of it”.⁴⁹ While Adorno wrote specifically about the suffering of the Holocaust, Sontag in *On Photography* describes a similar dilemma with war photography which made spectators increasingly numb to horrific images, or worse, increasingly encouraging the belief that seeing the photographs was its own form of action or advocacy. Sontag’s later writing, *Regarding the Pain of Others*, however, softens this claim by recognising many of the important aspects of war photography for both the subjects and the viewers, noting that photographs reiterate “what it’s like” and allow ‘foreign’ wars to be witnessed by others in some way.⁵⁰ The softening of her claims over time can be read alongside a consideration of Levinas’ work, which describes a more nuanced relationship between those that suffer and those who are witnesses to their suffering.

Levinas wrote that

a radical difference develops between suffering in the Other, which for me is unpardonable and solicits me and calls me and suffering in me, my own adventure in suffering, who constitutional or congenital uselessness can take on a meaning, the only meaning to which suffering is susceptible, in becoming a suffering for the suffering — be it inexorable — of someone else.⁵¹

The suffering for someone else’s suffering remains an important issue today, especially as technological advances and media bring people more consistent evidence of worldwide suffering. For Grehan, the debate is of direct importance

⁴⁹ Theodor Adorno, ‘Commitment’ in *Aesthetics and Politics* (London: Verso, 1977), p. 189.

⁵⁰ Susan Sontag, *Regarding the Pain of Others* (New York: Farrar, Straus and Giroux, 2003), p. 7.

⁵¹ Emmanuel Levinas, ‘Useless Suffering,’ trans. Richard A. Cohen, *The Provocation of Levinas: Rethinking the Other*, Robert Bernasconi and David Wood, eds. (London: Routledge, 1988), p. 159.

in performance and the efficacy of politicised work. While she recognises Levinas' claim "that when the other calls us we have no option but to respond", she attempts to theorise and problematise what a 'proper' response from an audience might look like.⁵² "This is not", Grehan writes "about being charged with a political function and being ordered to change the world. Instead it is about spectators working out how to respond and ultimately what responsibility might mean". Frank's writing in *The Wounded Storyteller*, complements this point about the working out of responsibility while addressing the efficacy inherent in the connection between the non-ill/ill or starrer/staree:

Living *for* the other is not, as Levinas describes it, an act of exemplary goodness. Person live *for* others because their own lives as humans require living that way. The self is understood as coming to be human in relation to others, and the self can only continue to be human by living *for* the Other.⁵³

Frank argues, therefore, that by looking at Levinas' theory of alterity, it may be possible that the relationship between starrer/staree is more than just one of pitiable or inquiring glances.

The starrer/staree relationship may, as Garland-Thomson argues, demonstrate a strong interconnectedness with tangible social effects. How should an audience respond when called by the Other, either directly through the nonfictional testimony, or through more traditional mimetic performance? For Grehan, no major interventions are realistically expected. Rather, Grehan describes the ideal effect of the Other's calling as a 'radical unsettling' or 'a nagging': "... it follows them, nags and irritates them, and although they might

⁵² Levinas cited in Helena Grehan, *Performance, Ethics and Spectatorship in a Global Age* (Basingstoke: Palgrave Macmillan, 2009), p. 6.

⁵³ Frank, p. 15.

attempt either to suppress these responses or to establish ways of being in the world with them, the nagging remains and demands consideration”.⁵⁴ Grehan, Levinas, Sontag and Adorno all wrote specifically about suffering in a strictly political sense — the suffering of people in war, international crisis, plague and famine — but I will apply this lens directly to how individuals with illness experience their lives, and how others experience those with illness and ‘their suffering’ especially by promoting an ambiguity between illness/non-illness which is useful when considering the overlap and interplay of the inter-human. The relationship between the stare in both political and philosophical modes (by Garland-Thomson/Sandahl & Auslander and Grehan/Levinas, respectively) are not mutually exclusive and I hope to demonstrate the efficacy in placing these various modes of watching/being watched in close proximity.

Liminality, Documentation and Distance

Throughout this introduction, I have deliberately shied away from defining the word illness, in part because of various definitions and meanings that the word has, and in part, because of the different mental images it inspires. I find these differences useful in highlighting the various experiences of spectatorship and in demonstrating that any claims to objectivity in such definitions are naive. For the sake of this next discussion, however, it is critical to highlight the one aspect ‘illness’ that is common throughout definitions — namely, that illness represents a *state* or *period* of poor health. When using the word illness it’s essential to distinguish illness from disease — which connotes a disorder of structure or

⁵⁴ Grehan, p. 7.

outside force which causes harm to the body — from illness which applies to disorder present over a period of time. Even when framed as ‘an illness’, the term defines the presence of an ailment over time. While the *Oxford English Dictionary* does contain both usages of the word (an illness and illness as a condition of being ill), it is the latter which is prioritised.⁵⁵ This distinction separates illness from both disease and disability which, although these terms have their own distinct history, are not employed as ontological states as much as they are as categorisations.

In *Theatre in Health and Care*, Emma Brodzinski identifies how illness, being a state as described above, might be thought of as a liminal state. She writes:

Symbolically, an ill individual enters a realm where s/he is exempt from the routine and convention of everyday life. So we might understand this realm as what anthropologist Victor Turner terms a liminal state. It is a time out of time where different social rules and conventions apply.⁵⁶

Similar to Parson’s ‘sick role’ described previously, Brodzinski describes how illness is a state defined in part by it being a time in which a patient is exempt from normal activity and responsibilities and takes on, as their role, a career as a ‘sick’ person whose main responsibility it is to get better.⁵⁷ Without their everyday roles and responsibilities, however, illness becomes a distinctly separate time where one may not necessarily be considered part of everyday functioning society. While battling the sickness becomes the person’s main function (perhaps allowing them to stay inside a paradigm of all bodies being functional or useful to some extent) this function is still considered a ‘time away’

⁵⁵ ‘Illness’, *Oxford English Dictionary* <<http://www.oed.com/view/Entry/91493?redirectedFrom=illness#eid>> [accessed 2 February 2012].

⁵⁶ Emma Brodzinski, *Theatre in Health and Care* (Basingstoke: Palgrave Macmillan, 2010), p. 27.

⁵⁷ Parsons discussed in Frank, p. 13.

from ordinary society. The focus of this ‘time away’ in illness, thus becomes understood as being the time it takes to get the body out of the liminal illness space and back into being a productive member of society — be it as consumer/work, or simply as an individual capable of self-determination. Tanya Titchkosky writes about the relationship between disability and ideas of liminality, writing that

In Western(ised) cultures, the tradition of medicine envelops most newly disabled people, for example, moving one back into the position of able-bodiedness through medical, remedial, or rehabilitative practice or by confirming one’s identity as disabled. But once disabled... limbo.⁵⁸

By differentiating illness and disability as objects of study, it is possible to examine what may be at stake in this pressure to ‘move one back’ into able-bodiedness that she describes and how this process may limit people with illness’ access to disability discourses, especially if disability studies are built predominantly around social and not medical models of disability — which is precisely the model through which the ill bodies are being seen. By thinking of illness as a liminal state, it becomes possible to understand the constant and perhaps frustrating flux of a person’s medical and social reality, both of which are never settled while inside of this place or duration of illness, nor exactly settled upon the illness’s completion.

Thinking of illness as a liminal space and as a state separate from the functioning everyday may usefully demonstrate how an individual’s experience during an illness needs to be looked at through a specifically subjective and phenomenological lens, which I will do in this thesis through my observation and interrogation of documentation. Such a lens would demonstrate how the apartness and in-betweenness of illness are intrinsic qualities to any study on

⁵⁸ Tanya Titchkosky, ‘Looking Blind: A Revelation of Culture’s Eye’ in Sandahl and Auslander, p. 225.

the subject. By looking at modes of spectatorship in *Playing the Cancer Card* to understand illness, I intend to examine the subjective nature of the experience of illness for both people experiencing illness and those who act as spectators to that illness. In order to highlight this goal, I will use performance documentation as my central object of study. By looking at an illness through the lens of documentation or the affects of the performance — as opposed to attempting a read on the illness/performance as a subjective analysable whole — the reading of that experience instantly becomes recognisable as subjective and, since not the *thing* itself, open to interpretation.

Rebecca Schneider, in her recent book *Performance Remains*, writes about the experience of attending a Civil War reenactment, the distance from which (both physically and temporally) opens up useful questions about how a lens of spectatorship creates an experience which is as much about presence as it is about rejecting any sort of objective claims to understanding. She writes:

Our witnessing was a kind of attention to the players' actions that could not, in this particular case, rely on images or on sight. When the reenactors rode and walked out of the woods again, everyone in the bleachers cheered. But what had we witnessed? Mostly we heard stories afterward of what it had been like...afterward.⁵⁹

In the case above, Schneider describes her subjective experience of spectatorship to a document, where here I am categorising the entire reenactment as a form of documentation of the Civil War — a claim that Schneider convincingly makes elsewhere in her book. As Schneider demonstrates, this lens of spectatorship — the experience of watching the reenactment as opposed to being a part of the reenactment — necessarily highlights the subjective experience of watching and witnessing.

⁵⁹ Rebecca Schneider, *Performance Remains: Art and War in Times of Theatrical Reenactment* (New York and London: Routledge, 2011), p. 33.

What is illuminating about Schneider's account is that she does not attempt to understand the reenactment — or by extension, understand the Civil War — completely, but rather takes stock in her own experience of watching the documentation, and specifically in what she missed as a non-participant.

Andrew Quick writes about how the witnessing of documentation can be frustrating but may also guide how documents can be read and considered, in relation to the object which they were documenting. He writes:

I have sometimes been seduced into thinking that the actual mechanisms and processes of how particular performances were put together were tantalizingly within my reach. And yet, I was also always conscious that so much is missed or excluded in all forms of documentation. A great deal happens off the screen and, of course, many important parts of the process never make the page. As such, it is impossible to grasp the totality of how a particular work is put together and it is necessary to acknowledge that the interpretive acts that are generated by an engagement with the archive are always speculative.⁶⁰

Because documentation highlights the experience of an audience member's non-presence at a given event (at least at the time of their consideration of the documentation if not from the event itself), as evidenced by both Schneider and Quick, writing on one's experience of witnessing documentation (or anything removed from the subject itself) can be a useful starting point for conversations on empathy, sympathy (and their potential impossibility). In *Playing the Cancer Card*, I will look, therefore, at the experience of illness through a consideration of my own spectatorship to various forms of documentation. Each different object for analysis — interviews with artists, online reviews of shows, video documentation, etc — create a barrier between myself/the reader and the work around illness (or the experience of illness) that is useful in this regard. This barrier provided the impetus for the creation of *Fun with Cancer Patients* — discussed and analysed in Chapter 4 — which uses ideas of separation

⁶⁰ Andrew Quick, *The Wooster Group Workbook* (New York and London: Routledge, 2007), p. 8.

between illness (or the event of illness) and an audience as a way to realign current conversations about sympathy or understanding individual embodied experience.

Performance documentation is the subject of Matthew Reason's recent *Documentation, Disappearance and the Representation of Live Performance*, discussed in detail in Chapter 1, which realigns previous discussions between the theoretical importance of the documented image and how it can be read by various audiences. Reason argues that it is an acknowledgement of documentation's particularities, and a mapping of these particularities onto a reading of a given piece of work, which provides the most exciting and fertile ground for theoretical consideration. The interest in documentation, Reason writes,

is not in documentations as passive and transparent windows on to performance, nor in condemning them as something problematic to be overcome or begrudged, but instead in using them as an interrogative opportunity by which we may interpret performance. The interest, in short, is in how these representations make performance knowable.⁶¹

Instead of being a 'thing' which can be easily or objectively understood, I will use Reason's consideration of how documentation makes things (performance or lived experience) knowable to demonstrate how a focus on spectatorship of these documents can highlight the document's subjective nature. Drawing on Phelan's claim that "the interaction between the art object and the spectator is, essentially, performative", I will look at documentation of performance as an art object in its own right, and highlight how the dialogic encounter between spectator and documentation brings a certain understanding of the experience

⁶¹ Reason, p. 3.

of illness.⁶² While, for Phelan, the excitement of performance comes from its liveness and the unrepeatable nature, I argue that performances (or other creation) about illness may function as their own form of documentation of lived experience to begin with, similar to Schneider's reading of Civil War reenactments. My research attempts to intervene in Phelan's work in *Unmarked* by demarcating the usefulness of performance documentation, not as a substitute for the performance itself, but as a mode of entering a dialogue across embodied experience.

An open and expansive definition of documentation will be employed for the project here. Instead of looking at how a spectator to a dance performance is different than a spectator to a painting, or different than a blog posting, I am interested in how people act as spectators to any and all of these different formats depending on their own history and respond with their own stories and experience. This process will allow the various objects of my enquiry — Bobby Baker's *Diary Drawings*, Rita Marcalo's live art performance, cancer blogs, non-fiction writing, fictional film, performance installation and more — to each be seen as documentation which performs for spectators in a distinct way. Jackie Stacey's *Teratologies* even considers bodies and scars as forms of documentation when she writes: "Like the scars that become permanent reminders of the tissue below the skin, these bodily memories mediate against a complete forgetting".⁶³ Stacey is not the only person who has seen scars in this manner and, in fact, the scar as document provides the basis for Kuppers' phenomenological writings in *The Scar of Visibility*, in particular when Kuppers

⁶² Peggy Phelan, *Unmarked: The Politics of Performance* (London and New York: Routledge, 1993), p. 147.

⁶³ Stacey, p. 100.

writes that scars represent a “meeting place between inside and outside, a locus of memory”.⁶⁴

While my definition of documentation is broad, I hope to demonstrate (in Chapters 2 and 5) that the rationale for documenting an experience with illness may be different than Derrida’s arguments made in *Archive Fever* in that not all documents which I consider will be the result of — as Derrida describes — a “compulsive, repetitive, and nostalgic desire for the archive, an irrepressible desire to return to the origin, a homesickness”.⁶⁵ By considering surgical scars as documentation as much as consciously, or professionally, created pieces of performance, or archival material, the research will inquire, What is the usefulness of remembering illness? Might the documenting of an illness be a conscious effort to minimise the value of the illness? What happens if people actively wish to forget although a document remains? How does a consciously-created document differ in affect from that which is forced onto a body, and can there be slippage between these two categories?

Many documents, as Stacey’s scars attest, are not the result of planning or of a nostalgic desire to archive, and not like Sophie Calle’s documented re-imaginings of stolen paintings from Boston’s Isabella Stewart Gardner Museum in 1990, chronicled by Phelan in *Unmarked*.⁶⁶ In the case of Calle, a conscious process was undertaken to remember the paintings and their absence from the museum, but in Stacey’s case, and with the case of many with scars, documentation happens *to* the body and not always as a matter of choice. In this thesis, I will include analysis of the experience of spectatorship to

⁶⁴ Koppers, p. 1.

⁶⁵ Jacques Derrida, *Archive Fever: A Freudian Impression*, trans. Eric Prenowitz (Chicago and London: University of Chicago Press, 1996), p. 91.

⁶⁶ Phelan, p. 146.

documentation both consciously and/or professionally created and documentation that remains on my own body and in my own mind. Earlier in the introduction, I began to draw some of these threads together in what Reason might describe as “archive of detritus”:

the archive as detritus turns around the presumptions of neutral detachment, objectivity, fidelity, consistency and authenticity; instead claiming partiality, fluidity, randomness and memory. And having abandoned claims to accuracy and completeness, such an archive is able to present archival interpretations, proclamations and demonstrations; consciously and overtly performing what all archives are already enacting.⁶⁷

In short, and what I hope to demonstrate throughout this thesis: we are not desperately trying to create an archive, we *are* an archive. This archive is built from documentation that artists and non-artists (myself included) create consciously as performed selves and professional artistic beings, and from the accidental, incidental moments that frame it all. In this way, a body of professional work like Bobby Baker’s *Diary Drawings* can sit alongside the music selections from Grant’s funeral which I will discuss in relation to *Or Else Your Friends Will Have to Do It*, in a manner which is illustrative of various modes of spectatorship. I hope to demonstrate that the projects use documentation to highlight the fallacy that, as Quick describes, these documents might house any sort of origins that provide access to the “actual source and beginning of things”.⁶⁸ Although this claim of distance may frustrate more than bring audience or spectators closer to a piece of work, it is precisely during this recognition of the distance when productive exploration can be done around how it might be possible to share experience across embodied realities.

⁶⁷ Reason, p. 54.

⁶⁸ Quick, p.8.

Brokering the Discourses

By demonstrating the distance that exists between those who experience illness and those who do not, I intend to bring the two seemingly-separate populations in dialogue with each other, and thereby examine the central performer/spectator or starrer/staree relationship explored in this thesis. I will use close readings of texts, including Lucy Grealy's *Autobiography of a Face* and Sontag's *Illness and Its Metaphors* to demonstrate how this relationship between the ill and non-ill has been conceived historically and in literature, and readings of current cancer blogs (such as Paul Nicholls' *Music is Disease* in Chapter 4) and performance work (such as Rita Marcalo's *Involuntary Dances* in Chapter 3) to exemplify how this separation between the 'ill' and the 'non-ill' affects both parties. For cancer patients in particular — as will be explored in Chapter 2 with Barbara Ehrenreich's *Smile or Die* — I argue that language around survivorship and positivity are clear indicators of an employment (by those not experiencing illness) of a medical model of disability, highlighting only cure and a certain kind of fight towards a cure, which seems to serve the interests of 'the well' while ignoring the particularities of the experience of illness. I aim to demonstrate that the 'wellness agenda' to be encoded with language applied by the 'well' onto the 'unwell' to make them once again whole, or 'well' yet again, yet again policing the illness/non-illness split. I argue that the chasm between the respective discourses of 'well' and 'not well' can be, to use Brodzinski's term, be 'brokered' through the consideration of documentation and the operation of spectatorship and applied both to national arguments on health and more personal reflections on illness and mortality.⁶⁹

⁶⁹ Brodzinski, p. 13.

Chasms exist between two different kinds of discourses which I shall look at in depth in *Playing the Cancer Card*: between those created by people with illness and those witnessing these people (insider/outside) but also between medical and non-medical discourses. This first chasm, between the ill and non-ill appear in nearly every source I consider, from Virginia Woolf's writing, to Barbara Ehrenreich's *Smile or Die*, and to Jackie Stacey, who writes about cancer-related literature appearing after a cancer diagnosis:

[Cancer books] are on every friend's bookshelf, in every shop window. A veritable 'cancer subculture' proves to have been thriving, but, like so many others, it remains invisible until it becomes relevant and then, as if by magic, it seems suddenly all-pervasive.⁷⁰

The categorisation of cancer as a subculture frighteningly demonstrates that cancer is a part of life away from life, as if affecting *those* people not *these* people; *these* people are defined as those who do not experience cancer, at least not at the current moment.

The second chasm I shall consider is between medical and non-medical discourses. As C. P. Snow noticed in his influential 1959 lecture *The Two Cultures*, the sciences and the arts have between them a "gulf of mutual incomprehension".⁷¹ Programmes such as medical humanities programmes, the Wellcome Trust and Performing Medicine (with which I have been involved extensively) attempt to bridge the gulf between the two worlds because of an understanding that the separation causes physical harm to people's health. The humanities may help to highlight social inequities in relation to medical access, and may highlight how patients are affected (physically and emotionally) by the language and structures of medical treatment. By recognising that these two

⁷⁰ Stacey, p. 2.

⁷¹ C. P. Snow, *The Two Cultures* (London: Cambridge University Press, 2001), p. 4.

types of chasms exist, it is possible to recognise opposing viewpoints without being prejudiced against either. This is of critical importance as I do not believe, or plan to make the claim that, any individual point of view is at fault for the chasm between ill and non-ill experiences, and/or personally responsible for the gulf between medical and non-medical discourses.

Because of the continued dichotomy between medical and non-medical discourses (and perhaps a bias against the publishing of books on cancer, which Mukherjee's 2011 Pulitzer Prize win with *The Emperor of All Maladies* may work to change), Stacey's 1997 book *Teratologies: A Cultural Story of Cancer* remains the seminal reading on how cancer and one's own cancer experience fits into contemporary discourse, and will provide critical framework for much of this thesis. I will extend Stacey's work through a consideration of contemporary performance and a consideration of not only my own cancer experience, but of my experience of being a spectator to other people's cancer experience. Stacey's work, like this project, also employs autobiography as essential to her arguments, writing at length about her own diagnosis with cancer as a major turning point and while she contextualises her diagnosis/treatment inside larger discourses about feminism and queer identities. The writing of the book (much as with Sontag's *Illness and Its Metaphors*) is predicated on the shifting of Stacey's position as someone who had not experienced cancer, to someone who did. I hope to look critically at how this double alteration (change in bodily experience and change in academic focus) plays out among other theorists and artists such as Jo Spence and Bobby Baker. I will also consider what might be problematic about learning from theory about illness or disability exclusively from people post-diagnosis or post-impairment. As Davis writes: "While many white people have embraced the

cause of people of colour, and while many straight people have taken up the cause of gay, lesbian, bisexual and transgendered people, few ‘normal’s have resonated with people with disabilities”.⁷² Considering my own writing and performance in relation to this question is an important consideration to the project as work around non-illness, I argue, doesn’t exist, primarily because of the current separation between ill and non-ill. I will address this question through a conversation about spectatorship: as theatre audiences are considered both as a collective and as individuals, I hope to be able to differentiate group experience (the popular narratives, the dominant discourses) from individual experience, both marginal and mainstream.

It is critical that the subject of cancer and illness be consistently reviewed because of the changing popular discourses around it, and about the changing experiences of people with cancer and illness. As Frank demonstrates about medical history, “Folk no longer go to bed and die [...] Folk now go to paid professionals who reinterpret their pains as symptoms, using a specialized language that is unfamiliar and overwhelming”⁷³ but even this is a relatively modern occasion. For myself, being someone treated with cancer in 2001, I would have no idea what cancer treatment looks like today, as medicines and medical research are constantly changing in both small and large ways. But, as will be discussed extensively in Chapter 4, narratives around cancer (looking at *Terms of Endearment* and *It’s Not About the Bike*) in their structure have not grown or changed significantly in twenty years, nor has the popular imagination around cancer, creating even further need for an extended study on cancer, especially in relation to performance and its capacity to stage and document

⁷² Davis, p. 4.

⁷³ Frank, p.5.

experience and narratives. I plan to demonstrate how technologies such as blogs may affect these experiences and narratives and also plan to demonstrate how my own work has focused on revitalising the classic/expectant cancer narratives, and how popular discourse generally continues to follow a predictable trajectory.

While *Playing the Cancer Card* is focused more specifically on spectatorship and the way documents about cancer and other illnesses are produced and witnessed, the theoretical work and the practice-based body of work I have created also seek to advance the subject. It does this by analysing different modes of performance and documentation, and also, especially in the case of my practice, relationships between performers and audiences particularly around the relationship between illness and how it is witnessed. With my research, I aim to draw attention to the fact that cancer narratives cannot be static and must be constantly revisited, particularly in relationship to contemporary popular and privately personal narratives. In this constant revisitation, a deeper understanding of the experience of illness may be possible for both the ill and those people who serve as spectators to that illness, recognising that, at various points in our life stories, we will each act as both types of people. Garland-Thomson writes about this reality in her defence for using 'we' throughout her writing, which applies to ideas of discourse-brokering:

The 'we' of [her] book is a rhetorical convention to draw readers into an identification with the book's point of view, with its contention that staring is a universal impulse [...] The rhetorical strategy is an effort to avoid the flattening pronominal dichotomy of 'we' and 'they' that divides starers from starees.⁷⁴

Because illness is more of a universal reality than a universal impulse, 'we' are 'they' and 'they' are 'we' at various moments in our personal journeys. Through

⁷⁴ Garland-Thomson, p. 10.

looking at how spectators exist on both side of the equation, and considering the distance between them at given times — but distinctly not being different populations altogether — perhaps a better understanding of either side can be forged.

Structure of Thesis

Playing the Cancer Card is structured in four chapters, each exploring a different aspect of how illness is performed, documented and read by others (and on occasions, the artists themselves). My methodology engages, first and foremost, with close readings, informed by research in relation to artist statements, projects, performances and documentation. This includes the reading of production notes, archived drafts, and published interviews by artists. The research will analyse the affect caused by performance, providing as much context as possible and creating close readings of texts following the methodological examples of Phelan, Koppers, Stacey and Heathfield. The research of Phelan, Koppers, Stacey and Heathfield, although disparate in their areas of study, each include explicit descriptions of their experience as spectators and contextualising information about the performance subject and often how their own work and personal lives intersect with the material. This is particularly important for me as I will include examples from my own previous performance work (*BALL, Other Funny Stories About Cancer, An Appreciation*) and will conduct an analysis of my own practice-based research project (*Fun with Cancer Patients*) as one of the performance examples. In addition to close readings of texts, I have also, where possible, interviewed the artists themselves. Because much previous work on illness has focused exclusively on biographical assumptions, muddying the critical discussions around

intentionality, I have interviewed Bobby Baker and Rita Marcalo in the hopes that they would be able to answer directly about their experience and artistic intentions. This process of interviewing Baker and Marcalo, however, is not uncritical and I hope to demonstrate a rigorous analysis of my interviews with them, allowing the interviews to become part of the affects of their performance, my chosen object of study.

Because *Playing the Cancer Card* also aims to relate the projects of individual artists to a broader public, I have conducted research on current patient advocacy work and popular examples of illness as discussed in the public sphere. This includes engagement with online fora, such as i2y.com (I'm Too Young) and youngadultcancer.ca (previously Real Time Cancer) as well as with current news media, which covers illness and the personalities (celebrities, non-celebrity celebrities and other newsmakers) with illness. The objective of the research, in this case, is to broker the chasms between performance and non-performance as well as medical and non-medical discourses in hopes that a more fluid dialogue will recognise how all are affected, to a greater or lesser extent, by these discourses. The research, I hope, aids in achieving a world set out by Frank (whose work I find both useful and problematic in various aspects, which I will explore) who writes about the current distance between medical and non-medical worlds:

In a multivocal medical world, non-medical voices would be heard. Physicians would take responsibility for their part in creating the 'other planet', and others would recognize that physicians do not create the world of medicine exactly as they choose.⁷⁵

In Chapter 1 — *Playing More than the Cancer Card* — readings of archival material from the work of Jo Spence and Bobby Baker demonstrate how non-production of creative work can be critically examined. Deploying

⁷⁵ Frank, p.147.

Sontag's framework in relation to performance and artists' personal histories, including my own, demonstrates how reconsiderations of non-actions make porous boundaries between ill and non-ill. Identifying this non-production here as active inactions, this chapter examines these active inactions by looking beyond the artistic production/cv of an artist and into the writing that they have done about their art creation and their decision-making processes. This chapter attempts to theorise about silence and what it might say about representation, illness and professional practice as well as creating a framework for accounting for this seeming-null set of case studies, this silence, which is, as John Cage describes, always 'pregnant with sound'. *Playing More than the Cancer Card* outlines how illness is experienced as much for the outsiders (spectators to illness) as it is to the ill themselves. The chapter will demonstrate how a rejection of artistic creation may be a method to limit these inequitable relationships between the ill and those functioning as spectators to that illness.

Chapter 2 — *Perverts and Postergirls* — analyses the interviews I conducted with Bobby Baker and Rita Marcalo to demonstrate how performance can spark tensions between communities formed (seemingly) around the same illness. Drawing on these artists' negotiations with marketing and media, I analyse the relationship between advocacy and artistry, building from the example of Bob Flanagan, whose simultaneous engagement with sadomasochistic practices and charity work raised provocative questions about how artists can be engaged in seemingly-divergent contexts. For both Baker and Marcalo, the occurrence of illness or the decision to 'come out' with a disability, respectively, offered a unique experience to speak publicly about their experience of health in venues more traditionally used for advocacy. This chapter will explore the tension that exists when artists interested in sharing

publicly about their bodies and experiences may have an arts practice that does not traditionally share the same goals as advocacy-driven institutions. These case studies will explore the affect of their performance work, more than just the performance event, to include both artists' responses to the demands of outside forces, their incorporation of online media coverage, documentation of the projects, and their reflections, which I have gained through personal interviews. By examining the role of spokesperson and artist, *Perverts and Postergirls* attempts to examine the border between personal artistic process, advocacy and the contested territory of compromise. This chapter builds off Chapter 1 by exploring more in depth the process of breaking silence and the benefits and consequences that may come with disclosure, especially when implied spectators or starers become literal starers or respondents to a piece of work and to an individual's life.

In Chapter 3 — Music is Disease: Cancer Blogs and Spectatorial Expectation — an analysis on Paul Nicholls's blog *Music is Disease* and related cancer blogs elucidates how the limitations imposed by traditional narrative structures around illness may be redressed by these real-time blogs. The chapter begins with a detailed examination of well-known 'cancer stories' (*Terms of Endearment*, Lance Armstrong's *It's Not About the Bike*) in relation to Jackie Stacey's work in *Teratologies* and Mark Currie's *About Time* to determine the expectations placed on top of a cancer patient and a cancer story. The chapter looks at different methodologies employed by bloggers, which interrupt expectations (from either real or implied starers) placed on more traditional cancer narratives and use the technology to address how cancer patients are watched. Finally, in this chapter, I investigate my performances — *An Appreciation* and *BALL & Other Funny Stories About Cancer* — and consider

these performances as an alternative to traditional cancer narratives, both in their placement (*An Appreciation* as a club act) and structure (*BALL & Other Funny Stories* performing a post-survivorship story).

Chapter 4 examines *Fun with Cancer Patients*, a practice-based research project funded by a Wellcome Trust Arts Award, and argues that by challenging depictions of illness, and addressing the social constructions around cancer, it may be possible to speak to audiences who both have and have not experienced cancer. The chapter takes its frame from *Picture Your Life After Cancer*, a *New York Times* interactive photoessay from 2010, which presents the stereotypical narrative of cancer — one littered with positive iconography and exclusively happy or redemptive endings. *Picturing Your Life* examines *Fun with Cancer Patients* and its two Actions (*Tommyknockers Tommyknockers* and *Guerilla Pub Quiz*), which challenged the expectations placed on traditional cancer story. This chapter also examines *Connotations 1994-1998* (1998) by Hayley Newman (1998), *Palestine* by Joe Sacco (2002) and *Traces* (2000) by Petra Kuppens as art pieces who inspired the creative process in distinct ways.

In the Conclusion, I consider two of my recent performance projects (*Carpe Minuta Prima* and *Or Else Your Friends Will Have to Do It*) that examine people's different embodied histories without foregrounding illness, and argue that understanding ourselves as spectators and objects of the spectatorship of others may help broker discourses between different embodied experiences. By drawing attention, at the end of the thesis, to how performances about 'universal themes' of life and death may work in a manner similar to those about specific illness, disease or disability, I aim to bridge chasms between discourses and experiences which I hope will be beneficial, especially to those who naively

think of themselves as unaffected by those outside their own embodied experience.

Overall, *Playing the Cancer Card* aims to contribute a passionate and personal voice to the theoretical frames of spectatorship currently circulating inside both performance studies and in medical humanities. The research will carve out a distinct place for illness inside of larger disability discourses, and provide lenses for understanding how embodied histories affects one's own experience of spectatorship. The political aim of the work, if I were to state a singular political aim, is to demonstrate how illness — currently considered a liminal state inside of which people are not taken as independent, powerful or productive — can be reconfigured as a distinct, yet not disconnected, part of the experience of life, and the ill as capable, thoughtful and empowered. While liminal spaces have been considered productive moments or work creation in relation to gender or sexuality, such theory has not been considered productively outside of a therapeutic contexts when looking at the liminal space brought about through illness. By brokering the discourses between different embodied experience, the research intends to begin the shading between discourses in a manner which is sensitive and efficacious.

Chapter 1

Playing More Than The Cancer Card: Illness, silence and active inactions in the work of Jo Spence and Bobby Baker

Jade Goody: Personifying an Age of Documentation

On 24 March 2009 *OK! Magazine* featured Jade Goody on its cover for the third week in a row. For two previous weeks, *OK!*'s subtitle read "First for Celebrity Weddings", highlighting the terminally-ill Goody's wedding.¹ After two weeks of celebration, commemoration preemptively commenced in anticipation of Goody's death. The subtitle to *OK!*'s 24 March cover read "With All Our Love and Prayers", and featured the headline "My Last Ever Interview and Final Pictures". Although no one could accuse Jade Goody of having denied the world access to her personal life — her on-screen cancer diagnosis exemplified contemporary fascinations with public access to private lives — "My Last Ever Interview and Final Pictures" made me still hungrier for more. More information, more pictures, more story, more time.

Jade Goody led a life obsessed with the trappings of celebrity, but even more so, led a life obsessed with the trappings of documentation and the documentation of ordinary and celebrity lives. Because Goody became a celebrity after appearing as a contestant on the television program *Big Brother*, it was not strange that she would continue to allow cameras to roll when facing cervical cancer. Although Goody maintained a fan base of well-wishers and cancer advocates, who labelled the UK's 20% nationwide increase in smear tests as the "Jade Goody effect", many early television and print media critiques

¹ Christian Guilteneane, *OK! Magazine*, 10, 17 & 24 March 2009.

were made of Goody's continued appearance on television.² The critiques — led primarily by authors of blogs and assisted by newsreaders such as Sir Michael Parkinson — centred on her perceived quest for fame and demonstrated a broader societal discomfort around illness. As Jane Ennis, former editor of *NOW Magazine* and self-proclaimed creator of Jade Goody Inc., wrote “[P]lease, please, please demand some privacy now”.³ Goody had been previously most famous for her ignorance of geography, for a racially-charged spat with Shilpa Shetty and for her Goody-endorsed products (such as Shh by Jade Goody Eau da Parfum Spray and Jade's Shape Challenge, a video workout) all cementing her status as B-list, non-celebrity celebrity tabloid fodder. As Fintan Walsh writes, “at the heart of this public disdain circulated deeply classist and misogynistic biases concerning public and sexual propriety”, causing “tensions surrounding which subjects counted as fitting popular objects of desire, and who fell beyond the domain of acceptability”.⁴ Although Goody did not define herself as an artist, she (and the people around her) worked tirelessly to craft a specific image of the non-celebrity celebrity — what Ennis described at Jade Goody Inc. — the output of which could be seen as an oeuvre in its own right.

After publicist Max Clifford announced that Goody's cancer was terminal on Valentine's Day 2009, all things Goody moved in quick succession, not the

² James Sturcke, 'Cancer tests go up after Goody diagnosis', *The Guardian*, 17 February 2009, <<http://www.guardian.co.uk/media/2009/feb/17/cancer-tests-jade-goody>> [accessed 26 December 2011].

³ Jane Ennis, 'I created the monster that became Jade Goody Inc...', *Mail Online*, 7 February 2009, <<http://www.dailymail.co.uk/tvshowbiz/article-1138397/I-created-monster-Jade-Goody-Inc--Now-I-feel-guilty-fights-life.html>> [accessed 3 November 2009].

⁴ Fintan Walsh, 'Between Deaths: Screening Jade Goody', *Contemporary Theatre Review*, 19, 3, 2009, p. 383.

least of which was the movement from discomfort and critique to undying love and respect for the “plucky” and “devoted” Jade Goody.⁵ A wedding, a christening and exclusive deals to the *Daily Mail*, *OK! Magazine* and *The News of the World* to document her final weeks (with earnings placed in a fund for her young sons) immediately followed suit. The thorough documentation of Jade Goody’s life, dying and death brings to the forefront a central concern of this thesis, namely the ways in which documentation crafts the experience of illness for both people with illness and spectators to their experience. Regarding the pre-emptive Goody memorial issue in *OK!*, Walsh writes that it “reveals just how strong the media’s desire was to control the terms of the woman’s life and death”.⁶ The sheer scale of the documentation of Goody’s life and death makes me consider what could come forth from an employment of the opposite: a rejection of documentation, an extreme privacy in the face of public interest and a silence which may pattern the quietness of hospital, the slowing of a career during illness and perhaps the quietness of the end of a life.

So what, in theoretical terms, is to be made of the work that is never documented, let alone produced? While there are some artists who play with documentation and the under-documentation of their work such as Tino Sehgal and Hayley Newman, little has been written that considers the ‘undone projects’ and the professional silences created by artists as an artistic choice or statement. The professional silences are most often considered through a biographic lens, critique quickly giving way to presumptions about the life of the creator. This process was much-discussed by Barthes in ‘The Death of the

⁵ Christian Guilteneane, *OK! Magazine*, 10 March 2009, p. 41, 49.

⁶ Walsh, p. 384.

Author', who warned that the critical practice of linking Van Gogh and his mental illness, for example, cheapen and limit the work he created.⁷ In this chapter, I will address the critical gap that has been created when theorists ignore personal illness when considering an individual artist's practice. Heeding Barthes' warning, I hope to avoid linking illness and given actions (or non-actions) without documented evidence and instead look at examples of theory and artistic reflection that incorporate the non-actions as part of a conscious process. By identifying what people (artists and non-artists alike) might gain from enacting non-action, personally, or be trying to say, aesthetically or artistically, the work here will move people with illness outside of the traditional "sick role" (as discussed by Parsons and Frank) which presumes that those with illness cannot be responsible for making decisions, which affect the world outside their personal experience, during their time with illness.

In the following case studies, I will use the work of Susan Sontag, Jo Spence and Bobby Baker to chart aspects of their aesthetic and artistic journeys. I believe that these examples demonstrate that work not created is not equivalent to artistic creation not considered. On the contrary, the decision not to create work may be the result of significant deliberation and reflection. By labelling these projects as active non-actions, I hope to open up the consideration of material not included in publications as essential to understanding an artist's process and politics concerning the ability and power of performance- or art-making. As Maurice Blanchot writes, "What we refuse is

⁷ Roland Barthes, 'Death of the Author' in *Image-Music-Text* (New York: Hill and Wang, 1982), p. 142.

not without value or without importance".⁸ The following examination of three artists and their seeming non-production in relation to personal illness attempts to examine active non-actions and consider how certain theoretical reconsiderations might imbue the seeming non-production with significant meaning. Because my thesis investigates how the illnesses of individuals are documented and performed for others, this chapter demonstrates that the process by which an illness becomes material for public consumption may not be as direct as an artist getting sick and instantly creating and presenting work. The investigation here demonstrates some of the factors which may encourage an individual to present (or not present) their work in a given manner or timeframe, and explores how the particular nature of illness as an embodied process may contribute to this decision-making process.

The following study relies on the writings of and statements by artists as much as possible in hopes of avoiding assumptions and/or a pop-psychologising of the performers or art-makers. This can be difficult and fraught territory particularly because, in many cases, the artists are no longer alive to explain their practice themselves and, in many cases, family members, colleagues and friends have attempted to account for these artists' practice as part of their own profession or artistic output. Relying on family, partners and colleagues for accurate information is constantly tinged with the knowledge that their relationship with the deceased plays strongly into how the living want the deceased remembered for both personal and/or professional reasons. This tension is no more clear than in the very public fight between Susan Sontag's

⁸ Maurice Blanchot, *Friendship* (Stanford: Stanford University Press, 1997), p. 111-112.

son, author David Rieff, and Sontag's partner, photographer Annie Leibovitz. These disagreements — which showed publicly through Rieff's memoir about his mother (entitled *Swimming in a Sea of Death*) and Leibovitz's response in multiple magazines — centred around the post-mortem photographs of Sontag and whether Leibovitz was ethical for publishing them.⁹ The arguments, although cloaked in more lofty debates about the ethics of photography, thinly veil an interpersonal tension between Rieff and Leibovitz based on their private family history.¹⁰ I have tried to look exclusively at first hand documentation provided by the creator, such as Sontag, themselves when possible, in hopes of sidestepping this issue. Regarding Sontag, this research may look significantly different in a few years, after Rieff completes the publication of Sontag's post-1963 journals.¹¹ In 2008, Rieff published *Reborn: Journals and Notebooks 1947-1963*, and has committed to publishing Sontag's journals from 1964 until her death in 2004.¹² Until their publication, however, I have attempted to employ a close reading of Sontag's own writings about silence as much as possible. I hope that this theory frames both a consideration of her work as well as the work of Jo Spence and Bobby Baker.

Misinterpretations of refusals and silences may occur (despite Blanchot arguing for a consideration of the importance of refusal or Sontag arguing for the aesthetic importance of silence) particularly when people are speaking for

⁹ David Rieff, *Swimming in a Sea of Death: A Son's Memoir* (London: Simon & Schuster, 2008), p. 140.

¹⁰ Cathy Galvin, 'Annie Leibovitz: Nothing Left to Hide', *The Sunday Times*, 5 October 2008.

¹¹ Sontag's 1963-1981 diaries will be released in April 2012, under the title *As Conscious is Harnessed to Flesh: Diaries 1963-1981* (London: Hamish Hamilton, 2012). It was still unpublished at the time of this thesis' submission.

¹² Susan Sontag and David Rieff, ed., *Reborn: Journals and Notebooks 1947-1963* (London: Picador, 2009).

those who cannot speak for themselves. I have included one such brief example here as a cautionary tale, both for the reader and for myself, in hopes that by acknowledging the potential slippery slope, I can avoid the fall. In her 1994 memoir *Autobiography of a Face*, Lucy Grealy lyrically traces the trajectory of the first half of her life. This life included cancer of the jaw (Ewing's sarcoma) at a young age, the removal of one-third of her jaw throughout her teens and twenties, countless difficult and unsuccessful cosmetic surgeries, and a life-long awareness of being seen as othered and/or "too ugly".¹³ While the book features these plot points with candour, the memoir is notable — and was critically well-received — for its attention to emotive detail and finely crafted passages about families in turmoil, beauty and difference.

After Grealy died of a heroin overdose in 2002, her friend Ann Patchett (well known for Orange and PEN/Faulker Prize-winning novel *Bel Canto*) began work on *Truth and Beauty: A Friendship*, a memoir which takes its title from one of Grealy's chapters and documents the two women's relationship. Patchett also wrote an afterword to *Autobiography of a Face* for its 2003 re-printing. While Grealy's family has accused Patchett of exploiting Grealy's 'disfigurement' and death in both the afterword and *Truth and Beauty* — Suellen Grealy writing "Ann, not so gifted, is lucky to be able to hitch her wagon to my sister's star" — it is the afterword which raises the most important considerations in relation to this research.¹⁴ In the afterword, Patchett claims:

We would often joke that at the end of her life, an event which we thought of as a long way off in the future, Lucy would write a

¹³ Lucy Grealy, *Autobiography of a Face* (New York: Perennial, 2003), p. 265.

¹⁴ Suellen Grealy, 'Hijacked by grief', *The Guardian*, 7 August 2004, <<http://www.guardian.co.uk/books/2004/aug/07/biography.features>> [accessed 2 February 2012].

sequel to this book call *Autobiography of a Face: The “Real” Story*. In this version, she would tell things absolutely as they happened, complete with all the sadness and pain and blame she had sidestepped in the first edition. One of the remarkable things about the book she wrote is how much she chose to spare us.¹⁵

With this claim, Patchett makes the entire book of *Autobiography of a Face* into *Autobiography of a Face: The “Real” Story*. Whether the decision was made by Patchett or HarperCollins Publishers, the addition of the afterword prevents *Autobiography of a Face* from being read on its own. More importantly, the afterword reframes the authorial intention of Grealy’s original work and revokes Grealy’s authority to determine its content. Although the “Real” story was alluded to, would Grealy have wanted it published in a single volume with the original text? It is difficult for Patchett to argue for Grealy’s work to be read as literature — as she does elsewhere in the afterword — while simultaneously arguing that the literature was not accurate to real life because of all of its strategic omissions. If nothing else, the afterword gives Patchett, not Grealy herself, the final word in understanding Lucy Grealy. In *The Wounded Storyteller*, Frank describes this difficult relationship between ‘truth’ and storytelling, writing, “If calling stories true requires some category of stories called false, I confess to being unsure what a ‘false’ personal account would be. I have read personal accounts I considered evasive, but that evasion was their truth”.¹⁶ By denying the ability of a Grealy to use evasion as a technique serving both her writing and perhaps, as Patchett claims, her psychological state, it is Patchett who denies Grealy the recognition as an astute literature writer.

¹⁵ Ann Patchett in Grealy, p. 234.

¹⁶ Arthur W. Frank, *The Wounded Storyteller* (Chicago: The University of Chicago Press, 1995), p. 22. Frank’s own emphasis.

Patchett's presumptions about Grealy's silence may be similar to those chronicled by Thompson's *Performance Affects*, in relation to how non-locals observe the silence or non-participation of seemingly-traumatised populations. Thompson links his observations to performance studies and to theory around applied theatre specifically, lambasting current practitioners who (even with the best intentions) create situations where practitioners demands people share narratives regardless of whether or not the sharing of that narrative is culturally specific or ultimately damaging.¹⁷ Thompson contrasts the work of psychologists Felman and Laub (who claim that withheld silence amongst Holocaust victims results in a "perpetuation of tyranny") with theatre-maker Munk, who describes performance in former Yugoslavia as employing an "eloquent silence". Thompson makes the insightful claim that:

Positioning silence against speaking reduces it to a passive failure rather than giving it any possibility for agency. Silence, in fact, could be an *active* means of coping at certain points in the history of a person's relation to an appalling experience.¹⁸

This chapter will precisely demonstrate this *active* process but intervenes with Thompson's work by investing in the theory and artistic output of performers and artists themselves, as opposed to reading their work from the perspective of facilitators and observers to the process. Thompson, however, provides a clear and humanising method of leaving open the silences which others either take for granted or fill with possibly-inaccurate meaning, as with Patchett above.

One of the major sadnesses surrounding a premature and sudden death, like Grealy's, is the inability for those nearest the deceased to process their

¹⁷ James Thompson, *Performance Affects: Applied Theatre and the End of Effect* (Basingstoke: Palgrave Macmillan, 2009), p. 45.

¹⁸ Thompson, p. 67. Thompson's own emphasis.

relationship in a meaningful and measured manner. While this is not to say that there is one ideal way to die, in the case studies presented here, there is a distinct bias towards artists who have the privilege of time and whose writing reflects a conscious and documented period of time in which illness could be recorded and reflected upon. Beyond that, each of these artists had people watching them, archiving their thoughts, and people interested in publishing their journals. This research intends to use these case studies as examples for how a person's silence, or inaction, might be observed in a different, more active and engaged manner.

Many people with illness observe the reality that they are constantly gazed at, looked to, prodded and watched. This was a situation I felt keenly as a patient myself, writing in *BALL*, "Me, me, me, can we please talk about someone else? I know that I have cancer..."¹⁹ In response to being stared at, prodded, looked to and watched, in some cases people with illness like Anatole Broyard (*Intoxicated by My Illness*, 1992) or Susan Miller (*My Left Breast*, 1994) will wax eloquent about their situation and how it is affecting their life.²⁰ In other cases, they will scream, yell, and protest, as is being done by Matthew Zachary and his i[2]y (I'm Too Young For This!) patient advocacy campaign discussed in greater depth in Chapter 2.²¹ What I hope to observe here is that moment when a person with illness refuses to say anything — when a person chooses not to

¹⁹ Brian Lobel, 'BALL', *Text and Performance Quarterly*, Volume 28, Issue 1/2, January 2008, p. 166.

²⁰ Anatole Broyard, *Intoxicated By My Illness* (New York: Fawcett Columbine, 1992) and Susan Miller, 'My Left Breast' in *O Solo Homo*, ed. Holly Hughes and David Román (New York: Grove Press, 1998).

²¹ Matthew Zachary, 'I'm Too Young For This Homepage', <<http://www.i2y.com>> [accessed 5 November 2009].

give spectators a seat to or a clear view of the show that is their illness. This can be a charitable act as such a behaviour was considered by Susan Sontag, or one more directly engaged with propriety and the good-manners involved in shielding others from difficult or stigmatising information, as the behaviour was considered by Bobby Baker.

Lucy Grealy never wrote *Autobiography of a Face: The "Real" Story*, perhaps because she died too young, or because she never intended to write anything of the sort. Because of the unexpected nature of her death, or perhaps because she consciously decided not to produce work or journals on the subject, her intentions remain an enigma. By examining the silences of other artists, though, it may be possible to understand that Grealy's *"Real" Story* may have been being told by her silence all along. By employing theory about silence by Susan Sontag and the process of finding language by Jean-François Lyotard, I will highlight how silence has been used productively in the work of Jo Spence and Bobby Baker. Although the current paradigm recognises documentation and public production as the central way to understand the lives of others — with Jade Goody being the most exemplary case — a consideration of Spence and Baker's work may demonstrate how different modes of understanding experience are possible.

Susan Sontag: Theorising the Silence

Susan Sontag begins *Illness as Metaphor* with the following: "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual

citizenship, in the kingdom of the well and in the kingdom of the sick”.²² Illness, Sontag reckons, although related intrinsically to wellness, is a kingdom away, a someplace else which implies a journey between. The concept of illness as another world or a world apart from wellness quickly brings to mind the literal separation of the ill — leper colonies, asylums, quarantines — as well as a more metaphysical or spiritual separations as chronicled by John Donne in *Devotions upon Emergent Occasions* (1624). Before reading Sontag, in my own writing of cancer in *BALL*, I described the experience of diagnosis as “being dropped in a foreign country where I did not speak the language, Cancer”.²³

In the years previous to *Illness as Metaphor*, Sontag’s *On Photography* included a similar discussion about places and passports, albeit this time in relationship to how individuals live their experience through documentation: “Photographs will offer indisputable evidence that the trip was made, that the program was carried out, that fun was had”.²⁴ One of Sontag’s central tenets throughout *On Photography* is that society relies on photographs to furnish evidence of an occurrence and this reliance alters lived experience: “A way of certifying experience, taking photographs is also a way of refusing it — by limiting experience to a search for the photogenic, by converting experience into an image, a souvenir”.²⁵ In her writing, Sontag remained unclear as to how she viewed photography and lived experience in relation to her own life, although from *On Photography* and *Regarding the Pain of Others*, and her relationship

²² Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Anchor Books, 1990), p. 1.

²³ Lobel, p. 165.

²⁴ Susan Sontag, *On Photography* (New York: Farrar, Straus and Giroux, 1977), p. 9.

²⁵ Sontag, *On Photography*, p. 9.

with photographer Annie Leibovitz, there was clearly a significant amount of personal interest. Thus, given Sontag's description of illness as a nation apart from the kingdom of the healthy, and the association of photography with journeys, it might be playfully assumed that a diagnosis of illness – or entrance into the kingdom of the sick – would result in Sontag creating a National Geographic-style exploration, blending intelligent text with glossy images.

Upon Sontag's diagnosis with breast cancer at an advanced stage in 1975, it was silence, in fact, which followed. Perhaps Sontag viewed her journey with illness as a journey distinct from her previous definitions of journeys – one in which the aforementioned *fun* was most certainly not had and documented. Perhaps this was the kind of journey in which a traveller is beaten and left for dead on the side of a foreign road: as in this case, tourists may be less inclined to photograph the police station than they are excited by the prospect of being home again. Even though photography was not her art form, Sontag chose not to document her personal journey in her writing either, or at least not in her published writing. Instead of documenting her own illness, Sontag composed *Illness as Metaphor*, described by her son David Rieff as “almost *anti*-autobiographical – intentionally so...”²⁶ In *Illness as Metaphor* Sontag considered societal fascination with cancer in relation to a historical obsession with tuberculosis. *Illness as Metaphor* explored how people with both TB and cancer have been blamed and marginalised for their disease, while also being a point of extreme aesthetic interest. This was written without Sontag putting herself, or her experience with breast cancer, explicitly in the text. Rieff,

²⁶ Rieff, p. 28.

in his memoir *Swimming in a Sea of Death*, describes Sontag's opacity to the outside world in her personal life as well as her professional life. Her only expression, he claims, was written in her journals, which are only now being made public in their entirety.

Sontag's journals and first-hand accounts from her intimate relations demonstrate that Sontag was responding to her illness not with an absence or lack of action, but with a personal and professional silence, what I would describe as an active non-action. It was Sontag herself that, in 1967, provided a rubric for understanding such active non-actions with her essay "Aesthetics of Silence" in *Against Interpretation*, enabling readers to begin theorising about what was contained in this seeming-void. In "Aesthetics of Silence", Sontag identifies four ways in which silence can be purposefully employed by creators: to certify the absence of thought, to certify the completion of a thought, to keep open dialogue for future exploration of thought and to emphasise that which was previously said by refraining from embellishment.²⁷ Although Sontag does not herself describe her public silence surrounding illness, the rubric above helps witnesses frame potential readings of her seeming-silence.

It is Sontag's rubric for understanding silence which will have the most direct impact on the following readings of Jo Spence and Bobby Baker. Sontag, however, is far from the only theoretician to have written on silence, with other prominent thinkers including Adam Jaworski and Stuart Sim.²⁸ In *Manifesto for Silence*, Sim interrogates theorists like Jaworski alongside Sontag and charts

²⁷ Susan Sontag, *Against Interpretation and Other Essays* (New York: Farrar, Straus & Giroux, 1966), p. 139.

²⁸ Stuart Sim, *Manifesto for Silence: Confronting the Politics and Culture of Noise* (Edinburgh: Edinburgh University Press, 2007), p. 157.

the extensive artistic fascination with silence and the power of formal emptiness or refusal, from Lawrence Stern's novel *Tristram Shandy* (1759) to Kasimir Malevich's painting *White on White* (1917), up through to John Cage's *4'33* (1952). Sim's work passionately positions silence as an enlightening and necessary life force, drawing from the history of silent meditation and charting recent research on the dangerous physical effects of noise pollution. He also works effectively to distinguish silence which derives from a personal decision and choice from silence which comes as a top-down, oppressive decree, described by Jaworski as a 'silence of politics'.²⁹ The work of Sim, Jaworski, Malevich, Cage and others illuminate a history of professional artistic rejection and acknowledge that these creators have had aesthetic concerns (not necessarily linked to illness or bodily experience as will be explored below) which they expressed using silence. The fact that Sontag wrote theoretically about silence and illness, while simultaneously producing professional and artistic silence surrounding her illness, demonstrates that the condition of illness may distinctly engender silence (or active non-actions).

By considering the distance between Sontag's published and unpublished work during her illness, it is not my intention to fill Sontag's silence with language based on assumptions or unjustified analysis. Although withholding her creative process was not Sontag's stated aesthetic decision, her private journals being made public posthumously may allow for such readings as this body of work is thereby extended. I would be hesitant to read too much into her journals (recognising the significant separation of published

²⁹ Adam Jaworski, *The Power of Silence: Social and Pragmatic Perspectives* (New York: Sage Publications, 1992), p. 155.

and unpublished material as I critique Patchett of not doing) had Sontag herself not alluded to this set of writing in *AIDS and Its Metaphors* years after writing (or not-writing) her work on breast cancer. It was made clear from Sontag's writing and subsequent publication of *AIDS and Its Metaphors* (published in a single edition with *Illness as Metaphor*) that underneath *Illness as Metaphor* was something personal, as if it were an afterthought to *Illness as Metaphor* that, ten years later, still yearned to be pronounced. It is this pronouncement that successfully brackets what came before. She concludes *AIDS and Its Metaphors* with the following:

The ill are neither unavoidable casualties nor the enemy. We — medicine, society — are not authorised to fight back by any means whatever... About the metaphor, the military one, I would say, if I may paraphrase Lucretius: Give it back to the war-makers.³⁰

Sontag's investment in silence in her personal life was similar to the silence experienced when Sontag was diagnosed with myelodysplastic syndrome (a precursor for leukaemia) as is chronicled by Rieff: "On the drive downtown, she stared out the window. Then, after five minutes or so, she turned away from the window and back toward me. 'Wow,' she said. 'Wow'".³¹ For Sontag who had cancer twice before leukaemia, words had never been hard to come by. And yet, with an increasingly-real sense of her own mortality, Sontag — according to Rieff — refused to speak language about illness, both privately with her son and close friends and publicly with her writing: "I can't write," she noted [in her journal], "because I don't (won't) give myself permission to voice

³⁰ Sontag, *Illness as Metaphor*, p. 179-180.

³¹ Rieff, p. 11.

the despair I feel”.³² This sentiment demonstrates how her public silence about her illness was filled with a number of possible meanings.

Sontag’s silence can be read as a generous act – sheltering the world from works of despair – or as more inner-directed, if Rieff is accurate when he states that “She revelled in *being*”.³³ Considered in relationship to her writing in *On Photography*, it could be that Sontag could not fully *be* with the presence of such mediation. In Rieff’s account, he describes his mother as a woman fiercely protective of her mortality. Sontag wanted her time, and perhaps without publishing deadlines or public statements, she could have it. Conversely, Sontag’s relationship to documentation and illness might be simpler. As Rieff writes, Sontag’s journals are riddled with the phrase “Cancer = Death”, which, left without embellishment or context, may suggest that Sontag viewed her experience as language-destroying. If her illness was not language-destroying, it at least altered her writing into something straightforward and devoid of the complexities which Sontag usually wrote about with such vigour.

It is perhaps because of this that Rieff took such great offence at the photographs taken of Sontag’s dead body by Leibovitz, describing them as a “carnival images of celebrity death”. To Rieff, Sontag “would not have had the time to mourn herself and to become physically unrecognisable at the end even to herself, let alone humiliated posthumously by being ‘memorialised’ that way...”³⁴ Between Rieff and Leibovitz, the absence of definitive instructions or statements from Sontag about such matters allowed both artists to make claims

³² Rieff, p. 140.

³³ Rieff, p. 139.

³⁴ Rieff, p. 140.

about Sontag's intentions. Now unable to speak for herself, their interpersonal dispute presents itself as a theoretical and critical schism between two people who claimed to know what Sontag 'would have wanted'. Although it is impossible to know definitively (and Sontag was famous for allowing her opinions to grow and change over time) Sontag herself may have provided a retort to Rieff's claim in 1978. In *On Photography*, Sontag wrote that

All photographs are *memento mori* [...] To take a photograph is to participate in another person's (or thing's) mortality, vulnerability, mutability. Precisely by slicing out this moment and freezing it, all photographs testify to time's relentless melt.³⁵

Sontag had no more *being* to spend time doing, and perhaps the literal connection between her death and the mortality brought forth by photography provided a clarity Sontag may have embraced. Sontag's consideration of illness was not without detractors, most notably D.A. Miller who, in 'Sontag's Urbanity' (1989), argued that Sontag's theorisation of language prevented political possibilities for people with HIV and AIDS.³⁶ Critiques like Miller's included, however, by considering Sontag's practice as artistic creator alongside the framework she created for her theoretical work it might be possible to witness her employment of mediation between herself and the 'thing' of personal illness, as an action deeply infused with meaning or, indeed, meanings. This process, I will argue, enables an analysis of other professional silences, such as those created by Jo Spence and Bobby Baker.

³⁵ Sontag, *On Photography*, p. 15.

³⁶ D. A. Miller, 'Sontag's Urbanity', *October*, 49, 1989.

Jo Spence: Embracing the Silence

Years before either woman had cancer, Susan Sontag was photographed by Jo Spence: an artist, educator and activist whose own entrance into the kingdom of illness created a major rupture in her working methodology and subject matter.³⁷ Jo Spence is now most commonly known for her work on breast cancer, and for her PhotoTherapy projects associated with illness. Spence's photography exhibition *The Picture of Health?* (1986) toured extensively and featured daily documentation of her breast cancer and alternative therapies used to put the cancer into remission. The photographs of Spence displaying her scars with text such as "Property of Jo Spence?" emblazoned atop her breast post-surgery, alongside her photographs of acupuncture and descriptions of her diet, expanded the dialogue about the dis/empowerment of the ill and remain iconic today. The photographs of her breast cancer treatment and scars are so iconic that individuals cite breast cancer as her cause death and *The Picture of Health?* a posthumous exhibition.³⁸ Spence, however, died of leukaemia, eight years after completing *The Picture of Health?* and her leukaemia caused in Spence, according to her own writing, a "crisis of representation" resulting in a professional and personal silence much different from Spence's previous treatment of illness.³⁹

³⁷ Photographs available at Jo Spence Memorial Archive or in Terry Dennett, *Jo Spence* (Slideshow, 2009).

³⁸ See, for example, Jane Richards, 'Centrefold/Spence of self: Jo Spence used photography to battle illness', *The Independent*, 7 September 1994, <<http://www.independent.co.uk/life-style/centrefold--spence-of-self-jo-spence-used-photography-to-battle-illness-1447158.html>> [accessed 2 February 2012].

³⁹ Jo Spence, *Cultural Sniping: The Art of Transgression* (London: Routledge, 1995), p. 21

While Sontag wrote about lives being experienced through photography, it seemed almost obvious that Spence — known for challenging photographic traditions and a focus on the personal — would document her illness through her camera. In text surrounding her first photographs, Spence wrote, “As [the doctor] referred to his notes, without introduction, he bent over me and began to ink a cross onto the area of flesh above my left breast”.⁴⁰ The violent intrusion of the doctor forced Spence to re-evaluate her relationship with her own self-image, a self-image informed by a life as a professional photographer and artist:

I realised with horror that my body was not made of photographic paper, nor was it an image, or an idea, or a psychic structure [...] it was made of blood, bones and tissue. Some of them now appeared to be cancerous.⁴¹

If Spence previously conceived of her body as an image or psychic structure able to be photographed, it appears that here she demonstrated that artistic metaphor necessarily made way for bodily reality post-diagnosis with cancer.

This experience of corporeality, and illness specifically, has a long history in both literature and theory. In 1985, Elaine Scarry marked out the territory in the most distinct way with her writing in *The Body in Pain*, writing that “[i]t is precisely because [bodily trauma] takes no object that it, more than any other phenomenon, resists objectification in language”.⁴² The embodied experience isn’t *like* or *as* anything: it simply *is*. While this seemingly-essentialised ontological state is subject to many outside biological and cultural frameworks

⁴⁰ Jo Spence, *Putting Myself in the Picture: A Political Personal and Photographic Autobiography* (London: Camden Press, 1986), p. 150.

⁴¹ Spence, *Putting Myself in the Picture*, p. 151.

⁴² Elaine Scarry, *The Body in Pain* (Oxford: Oxford University Press, 1985), p. 5.

of perception, Scarry's *is-ness* of embodied experience resonates with Spence's experience of illness . This loss of language became clear to Spence months after diagnosis, and follows classic definitions of trauma, such as those proposed by Cathy Caruth.⁴³ For Caruth, citing psychoanalysis, repetition and reconfiguration work to assess the catastrophic events not at the moment of impact but only in the future.⁴⁴

Caruth's work on Freud may be sharply contrasted with Thompson who takes the position that "The idea that trauma leads, for example, to an uncontrolled return of the past in the present [...] while providing a rich canvas to sketch the debates on representation or 'speakability', in fact has only limited support in empirical research".⁴⁵ Regardless of how the trauma is framed in relationship to the present and past, Thompson's intervention in such discourses on trauma are essential here in that they recognise how a relationship to narrative and trauma can be culturally specific. He writes, "Rather than assuming that populations are 'traumatised' and can be relieved through narrative-based storytelling, the chapter argues for an ethnographic emphasis that accepts different models of suffering and necessarily different modes of survival".⁴⁶ While I don't intend to claim that Spence is part of a different cultural context than that which supports psychoanalytic theory, I employ Thompson's precision in recognising cultural specificity to support my argument that Spence's usage of artistic language and technique demonstrate

⁴³ Spence, p. 151.

⁴⁴ Cathy Caruth, *Unclaimed Experience* (Baltimore: Johns Hopkins University Press, 1996), p.2..

⁴⁵ Thompson, p. 44.

⁴⁶ Thompson, p. 9.

a personalised and artistically-specific mode of interacting with trauma. It is, therefore, because of her inability to *incorporate* the illness artistically that Spence initially spoke of her difficulty creating cohesive work or personal narratives around illness.

A useful way of considering Spence's initial experience with cancer with regards to her loss of language is through *the differend*, a frame established by Jean-François Lyotard in *The Differend: Phrases in Dispute*. Lyotard defines the *differend* as "the unstable state and instant of language wherein something which must be able to be put into phrases cannot yet be".⁴⁷ The *differend*, according to Lyotard, goes beyond the usual 'one cannot find the words' by interrogating what may be at stake in not being able to find the words to describe a situation. Lyotard draws an example from the testimony of Holocaust-denier Robert Faurisson, who claimed that because no one had provided first-hand testimony of the gas chambers, they may not have actually existed. Lyotard combats this opinion (simply reminding readers that all who experienced the gas chambers are now dead) and describes the *differend*, in legal terms, in which "a plaintiff is divested of the means to argue and becomes therefore a victim".⁴⁸ The critical importance of the *differend* is this connection to legal matters and the stakes that are related to such matters. In legal cases, there is something of value to be lost or gained when one is able or unable to defend oneself. These stakes are comparable to how an artist like Spence may view the artistic language she had built over her career, and the problems that

⁴⁷ Jean-François Lyotard, *The Differend: Phrases in Dispute*, trans. Georges Van Den Abbeele (Minneapolis: University of Minnesota, 1988), p. 13.

⁴⁸ Lyotard, p. 9.

may arise from a divestment of that language. While Spence had developed, over many years, a language with which to understand her body (as a woman and as a woman from a working class family), the diagnosis of her cancer appears to have changed this body and the experience of embodiment much as Scarry describes above. For Spence, her body seemed to ‘resist objectification in language’ although Spence’s language was a photographic one. Although the personal experience of cancer is not comparable in scale to the Holocaust — as I will explore in Chapter 3 — the experience of illness may provide a moment of narrative wreckage which Frank, as I’ve quoted previously, recognises as endemic to postmodern times.⁴⁹ “What is at stake in literature”, Lyotard continues, “in a philosophy, in a politics perhaps, is to bear witness to *differends* by finding idioms for them”.⁵⁰ The act of witnessing, therefore, is an active one, in that it requires a person’s presence so that the finding of idioms and the making of meaning for new situations can occur. From a professional artistic perspective, Spence appears moved by such an action, her work quickly developing an idiom that would express her new political and bodily reality.

Spence did find a cohesive idiom and narrative surrounding breast cancer, and quite quickly as well. Although her first texts, quoted above, demonstrate this treatment of illness as somewhat of a *differend* — without comparable language — her photographs from this period seemingly belie such an internal struggle. The photographs in *The Picture of Health?* confidently explore the infantilising of patients and representations of the ill female body. Documentary photographs are blended with text and with staged photographs,

⁴⁹ Frank, p. 68.

⁵⁰ Lyotard, p. 13.

exposing what Koppers in a similar context describes as “the transparency of visual truth as construct”, which alerts viewers to their own subjectivity in witnessing, while drawing attention to the processes by which the work is created.⁵¹ On her body, Spence scrawled words such as Monster across her chest, aggressively engaging the audience with a reading of her body which challenges norms of the ‘pitable’ body and implores them to consider whether Monster is a self-definition by Spence or the expectation that Spence has on the viewer’s definition of her. This ambiguous territory may demonstrate one of the strategies in which a staree — or object of a public stare, as framed by Garland-Thomson, discussed in the Introduction — looks back, and engages with stare of the viewer and their judgements/concerns which are clearly culturally inflected and informed.

In *The Picture of Health?* text was also used to create the collages which toured collectively around the UK, Spence often reprinting the same photographs with different accompanying texts. Her staged photographs nearly all included what Spence described as an Intruder, inspired by Brechtian alienation, which would prevent the viewer from thinking of the photograph as objective reality. In one unnamed photograph in her *Picture of Health?* series, Spence stands in profile, one arm above her head, posed as if to perform a breast self-examination.⁵² What could be a typical breast cancer awareness poster is interrupted by the large motorcycle helmet worn by Spence, which prevents the spectator from reading any expression or feeling as though they

⁵¹ Petra Koppers, *Disability and Contemporary Performance: Bodies on Edge* (London: Routledge, 2003), p. 21.

⁵² Spence, *Putting Myself in the Picture*, p. 161.

can identify with the subject's experience. Throughout *The Picture of Health?* Intruders such as motorcycle helmets or sunglasses help to highlight another critical Intruder in her photographs — the scar on her left breast.

Spence's photographic practice of employing Intruders was not purely a function of her cancer diagnosis. Spence had previously railed against the classic idea, espoused by Barthes, that "[e]very Photograph is a certificate of presence"⁵³. Although not responding to Barthes directly, Spence highlighted those images which are not included in history: "In my early photographs there is no record of my appalling health [...] no record of the pointless years shunted around schools inside formal education [...] no record of a broken marriage..."⁵⁴ If photography managed to provide such an incomplete slice of life, it could not be depended on to certify presence. It was these beliefs that infused Spence's early projects with Photography Workshop, Hackney Flashers and the Crisis Project, all of which employed a politically potent subjectivity and methodology, which railed against the photographic convention to 'smile for the camera'.⁵⁵

While Spence rejected some canonical photographic theory (in particular, when she was in control of her photographs and subjects), she could embrace Sontag's idea that "photographs furnish evidence", thus allowing for accurate re-evaluation of treatment course.⁵⁶

I asked Maggie to take photographs of my alternative treatment as a confirmation that I had made the right choice [...] In some way,

⁵³ Roland Barthes, *Camera Lucida* (New York: Hill and Wang, 1980), p. 87.

⁵⁴ Spence, *Putting Myself in the Picture*, p. 82.

⁵⁵ Spence, *Putting Myself in the Picture*, p. 155.

⁵⁶ Sontag, *On Photography*, p. 5.

these photographs were like my advocate's eye saying I needed to do these things to become well.⁵⁷

This difficult relationship with photographic conventions was highlighted in an essay by Barbara Rosenblum in *Family Snaps*, a publication edited by Spence in 1991. Rosenblum, problematising documentation of her own breast cancer asks, “[w]hat if capturing my subjectivity is not the aim of documentary photography? What if the photographer decides that capturing her own subjectivity through images that are stirring to her is the most important thing?”⁵⁸ Spence’s autobiographical photography attempted to be a response to these issues, putting her own subjectivity and the subjectivity of any collaborators explicitly into the frame as is evidenced throughout *The Picture of Health?* series, and in particular with her photo/text collages.⁵⁹

After Spence successfully put her breast cancer into remission and toured significantly with *The Picture of Health?*, Spence was diagnosed with leukaemia in 1993. And then came silence. About her diagnosis, Spence wrote: “How do you make leukaemia visible? Well, how do you? It’s an impossibility. It’s what I went through before – a crisis of representation”.⁶⁰ Unlike her previous crisis of representation, Spence did not ‘solve’ the crisis that leukaemia presented. If, in the past, Spence considered herself in a situation resembling that of the *differend*, here it made a much stronger, more permanent presence. While breast cancer, with its visible manifestations, brings into focus the

⁵⁷ Jo Spence, *Cultural Sniping*, p. 21

⁵⁸ Barbara Rosenblum in Jo Spence and Patricia Holland ed., *Family Snaps: The Meaning of Domestic Photography* (London: Virago, 1991), p. 243.

⁵⁹ Jorge Ribalta, ed., *Jo Spence: Beyond the Perfect Picture* (Barcelona: Museu d’Art Contemporani de Barcelona, 2005), p. 269.

⁶⁰ Spence, *Cultural Sniping*, p. 215.

exposed female body, leukaemia, as a cancer of the blood, exposes little in a visible sense. Leukaemia exposes so little that Susan Sontag, in her original manuscript of *Illness and Its Metaphors*, noted that leukaemia was “the only clean death from cancer, the only death that can be romanticised”.⁶¹ Written more than twenty years before Sontag’s own diagnosis with leukaemia, her notation of the disease’s ‘cleanliness’ contextualises Spence’s crisis:

I’m dealing with an illness that is almost impossible to represent. I have not the faintest idea how to represent leukaemia except for how I feel about it. [...] Now that I have leukaemia, the language that worked with breast cancer doesn’t seem applicable.⁶²

While the *differend* experienced around breast cancer eventually ended in the finding of language and the ability to create art about breast cancer, it is here that Spence finds herself in a similarly, but more intensely, articulated situation.

With her new illness, Spence’s lifelong interest in representation and challenging codes of representation seemed to end abruptly. Leukaemia turned Spence’s attentions inward, and she focused less attention on her interaction with the outside world. If she had nothing to say to the world about her illness, this time around, she would not say anything at all:

This time around, I’m spending my time trying to decide what story my illness is telling *me* rather than trying to impose a narrative onto other people that I still don’t even understand myself [...] So it is possible I will never be a photographer or an artist again.⁶³

Because Spence described her professional artistic response to her leukaemia and published her thoughts, her inaction becomes witness-able as what I would describe as an active non-action, one which used professional silence

⁶¹ Rieff, p. 79.

⁶² Spence, *Cultural Sniping*, p. 215.

⁶³ Spence, *Cultural Sniping*, p. 216. Spence’s own emphasis.

strategically, which can be read productively through Sontag's aforementioned rubric for understanding silence. Spence, through her description of the 'impossible' task of representing leukaemia visually, clearly "[certifies] the absence or renunciation of thought" that Sontag describes – not out of a lack of effort, but out of a lack of possibility.⁶⁴ The second use of silence Sontag describes, the "certifying the completion of thought" is also present, but only if one considers Spence's entire career. Spence has thought about representation throughout her career and her absence of creation surrounding leukaemia brackets her thoughts on representation in a specific way, as if proving that the cancer, which has no apparent physical symptoms, remains impossible to represent visually.

The third and fourth usage of silence proposed by Sontag – "providing time for the continuing and exploration of thought" and "aiding speech to attain its maximum integrity or seriousness" – also appear in full force but in surprising ways. The continuation and exploration of Spence's thought regarding her illness, has seemingly less to do with representation than with Spence's reconsideration of her mortality and personal quality of life:

When I say to people I'm retiring, they say, "Yes, but you'll get better", and I say "Yes, but I won't want to do the same work. It's time to stop being a mother to the world and instead turn my energies inward for the first time. [...] I don't really want to have to think about the *politics* of leukaemia..."⁶⁵

Considering Sontag's fourth usage of silence, it is the documentation of Spence's early death, and the narrative it forms, which most help her work attain its maximum integrity or seriousness. The documentation of her life

⁶⁴ Sontag, *Against Interpretation*, p. 139.

⁶⁵ Spence, *Cultural Sniping*, p. 214. Spence's own emphasis.

performs for us as spectators and allows us to place the evidence of her photographs into a digestible narrative which tells us the story that Spence was deadly serious about her crisis of representation.

Terry Dennett, Spence's longtime collaborator and curator of the Jo Spence Memorial Archive held in London, has published several posthumous works from *The Final Project* (1991-1992)— Spence's experimentations around leukaemia and mortality — but most of her work from the period of her leukaemia remains unpublished and unsorted 15 years after her death. The Jo Spence Memorial Archive is accessible to the public through Dennett, who works diligently to promote her earlier projects and contextualise the experimentation that made up *The Final Project*. Her experimentation, according to Dennett, “was attempting to go beyond film in her search for a more allegorical statement on mortality” and played with montage predating digital imaging.⁶⁶ The decision to work with montage demonstrates an adventurous attempt to move beyond the medium of photography but also demonstrates a practical consideration. With decreased energy, it became easier to put slides together than to stage photographs. While there is not an absolute silence from Spence's *Final Project*, her stated desire to experiment with non-creation, as well as the lack of major showings of *The Final Project* create for her audiences a void pregnant with meaning. Spence's life story, read in conjunction with her texts and photography, demonstrate the multiple usages of silences explored above that are functions of both the work she produced and spectators' readings of her work following her death.

⁶⁶ Terry Dennett in Ribalta, p. 28.

Bobby Baker: Using the Silence

Over the past ten years, performer and live artist Bobby Baker has played with ideas of silence in relationship to mental illness, which in Baker's case was diagnosed in 1997. Baker's early work focused on the domestic and autobiographical, creating a rich body of performances and live art chronicled (with Michèle Barrett) in *Redeeming Features of Daily Life* (2007), which also includes essays and responses from a number of academics and fellow artists.⁶⁷ Baker's work was (and continues to be) infused with an energy different than that of Spence's but remains similarly political. Their similar usage of consciously-withheld professional production is what I will bring together in this chapter, although differences between the two women's works are legion. While Spence's pain and process were more knowable to an audience, Baker's projects allowed unexpected and serious themes to arise from playful, polite situations. As Marina Warner writes on Baker's installation *An Edible Family in a Mobile Home* (1976) (in which rooms were filled with life-sized edible statues of her family members), "the piece was a profane communion, a family tea party in which the family was eaten, so that the most polite, indeed genteel, national ritual of friendship became an ogre's banquet".⁶⁸ Politeness, profanity and manners have been a recurring theme through Baker's work, so when she began treatment for a borderline personality disorder in 1997, and because of the stigma around mental illness, it is not surprising that the subject was not instantly used as source material for public performance.

⁶⁷ Michèle Barrett and Bobby Baker, *Bobby Baker: Redeeming Features of Daily Life* (London and New York: Routledge, 2007).

⁶⁸ Marina Warner, 'The Rebel at the Heart of the Joker' in Barrett and Baker, p. 101.

When Baker became a patient at the Pine Street Day Centre in 1997, she simultaneously began a private project of doing a diary drawing every day at the Centre. While she expected her stay at the Centre and with mental illness to be short, she spent over 11 years receiving medical care: 159 of the 711 diary drawings she created comprised the exhibition *Bobby Baker's Diary Drawings: Mental illness and me, 1997-2008* at the Wellcome Collection in London, which I will discuss below and return to in Chapter 2.⁶⁹ In 1997, it had been years since Baker had created purely visual art. Even so, Baker had never started her diary drawings with the intention that they be shown publicly, so when she began creating diary drawings, her shift in artistic output did not publicly read as a shift in aesthetic style. Similarly, the silence discussed above with reference to Sontag and Spence is concerned with a lack of public dissemination of professional production, and does not touch on *private* artistic production. In this regard, I hope that an exploration of such private artistic production may expand critical debate around such silences. Art was made by Baker, yet did not participate in the regular economies of the artistic market. The diaries were private, and this lack of inclusion into her public persona as artist may exemplify some of the shame associated with mental illness, a public misunderstanding which ultimately leads people to keep illness to themselves. Jackie Stacey, who identifies her cancer as an illness with similar shame associated with it, writes about concealment in *Teratologies*:

Concealing the illness, the effects of treatments, the distress of the diagnosis often contribute to the stress of the whole

⁶⁹ Griselda Pollock, in Barrett and Baker, pp. 251-267, provides readings of individual paintings before the Wellcome Collection exhibition was created. My readings expand on her work by considering the paintings together as an exhibition and consider the production strategies made visible during the process of making individual paintings into an exhibition.

experience. Don't upset this friend or relative, hide it at work, keep it from your children. The cultural imperatives of secrecy and disguise are a constant reminder of the price of living with a stigmatised illness.⁷⁰

As Baker's work had previously explored domestic codes, with a careful eye on manners, the privacy regarding her illness may be an extension or expression of good manners and propriety, most often the same concerns which prevent people from speaking frankly about mental illness.

Bobby Baker's silence around mental illness ended in 2000 with her performance *Pull Yourself Together*, which proved for Baker a radical change in her overall performance form. Baker strapped herself to a chair on the back of a flatbed truck, with megaphone in hand, and screamed "Pull yourself together!" at strangers in and around Trafalgar Square in London. Clare Allen, writing on the performance, notes that pedestrians were shocked or angered to be yelled by a stranger on the street.⁷¹ This shock, shame or anger experienced by spectators quickly abated when the truck passed further and revealed a sign on its back which reminded observers that it was Mental Health Action Week, as if being 'for a good cause' lends legitimacy to any discomfiting public intervention. The public nature of the performance and its brash sensibility highlighted the silence around mental illness, which Baker hoped to challenge and to expose. Ending this silence is one of the major advocacy goals of organisations like Mind, whose Time for Change campaign includes major anti-

⁷⁰ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (London and New York: Routledge, 1997), p. 67.

⁷¹ Clare Allen, 'Bobby Baker: Pull Yourself Together' in Adrian Heathfield, ed., *Small Acts: Performance, the Millennium and the Marking of Time* (London: Black Dog Publishing, 2003), p. 131.

stigma advertisements in hopes of creating a more receptive environment for practical discussions about mental health.⁷²

Though *Pull Yourself Together* represented a strong introduction of mental illness in her work, Baker cites the taboo around mental illness, and speaking publicly about mental illness, as a factor which forced her to continue working and producing while receiving extensive medical attention for her illness. Perceiving or feeling that she would be unable to use mental illness as an excuse for taking time off (as people would not think it sufficient cause to interrupt work) Baker felt strong pressure to be productive in the world outside of mental illness. Although I had discussed this point with Baker in a personal interview in 2008, these thoughts remained professionally unpronounced until March, 2009 and *Diary Drawings*. The exhibition's 157 diary drawings (photographed by Andrew Whittuck) exposed the public to the work Baker had previously withheld from public view. As perhaps a final step in filling in the silence, the diary drawings are accompanied by additional context – text describing the outside world and events in her personal and professional life – locating and describing the previous silence.

Unlike Spence, the disjuncture experienced with her illness was not a matter of aesthetics, but of public professional production. The location of silence, inside Baker's life and career, existed where Baker continued to create professional work not about illness while creating a body of work that remained unshared with the public. Writing about the period of her illness from Day 317-397, Baker notes "It's hard to believe now that I kept juggling such a range

⁷² 'Time to Change Campaign Homepage', *Mind*, <<http://www.mind.org.uk/timetochange>>, [accessed 4 November 2009].

of extreme experiences and responsibilities”.⁷³ These responsibilities included the creation of Baker’s successful solo performance *Box Story* (2001). Because of what is depicted in *Diary Drawings*, it can now be understood that the outward success of *Box Story* did not coincide with internal calm or professional satisfaction. Accompanying a diary drawing from Day 385 – in which a pained Baker carries a globe like the statue of Atlas – Baker comments “*Box Story* toured for the next five years here and abroad. People loved that show so much everywhere I went. Keeping going with a message of triumph over misfortune felt like this image – it made me rather cross actually”.⁷⁴ While Baker uses *Diary Drawings* to inject language into the silence associated with mental illness, it simultaneously highlights that silence as a very real – perhaps inescapable – aspect of mental illness.

On Day 663 of her diary drawings, Baker’s relationship to illness and body changed yet again when she was diagnosed with breast cancer. Diary drawings continued for Baker – her mental illness was still being treated – but no additional projects were taken on in response to this new experience of cancer. In fact, although she found chemotherapy and radiation to be difficult challenges, the obvious outward symptoms of cancer such as hair-loss allowed Baker to stave off pressure to continue producing at her previous pace during treatment, as she had with mental illness.⁷⁵ A strong example of such pressure is clear from Day 364, a diary drawing featuring Baker performing *while* surrounded by text screaming: “Control for Two Weeks. Shows”. The pressure

⁷³ All quotations from Wellcome Collection exhibition of *Diary Drawings* taken from the text accompanying each drawing. Text published in exhibition hand-out.

⁷⁴ Accompanying exhibition text.

⁷⁵ Personal interview with Bobby Baker, 1 July 2008.

she felt at continuously producing work during treatment for mental illness seemingly dissolved with the introduction of a physical illness clearly readable by outsiders. The clear signification system associated with physical illness and the difference of it and the signification system surrounding mental illness demonstrate perhaps one reason why mental illness continues to demand such silence and taboo when discussed publicly. While mental illness remains wildly misunderstood (especially in how it exhibits itself in individual patients), the bald head (which Baker experienced), weight gain/loss and scars related to cancer (as will be discussed in Chapter 3) have been codified as if to ensure instant identification.

If Spence found that her breast cancer facilitated significant creative work, Baker found that her breast cancer facilitated a freedom from needing to create work. Baker often spent time completing small home chores and other projects suited to her lower energy level. Just as Spence had taken her diagnosis with leukaemia as a time for reflection, Baker realised that her cancer diagnosis would allow her to take this time whereas mental illness had not. During my interview with her, Baker reminded me that this had little to do with physical ability — she was closer to death, and closer to death more often, when undergoing treatment for mental illness than during cancer treatment — but had much to do with the fact that people *understand* cancer and its severity whereas mental illness remains a nebulous and taboo subject for many. Baker was encouraged to see how, in the past decades, cancer has transformed from

being a similarly taboo subject into something more openly discussed and Baker hopes a similar movement will happen around mental illness.⁷⁶

The lack of understanding around mental illness has made Baker a spokeswoman of sorts for increased education and public engagement around the issue. Her biography for the Wellcome Trust playfully explores this, stating: “Over the past 11 years [Baker] has periodically gone mad and is an active campaigner for more acceptance of and human rights for people categorised by society as ‘disordered’”⁷⁷. According to the Wellcome Trust’s website, the mission of the facility which housed Baker’s *Diary Drawings* is to “bring to life Sir Henry Wellcome's vision of a place where people could learn more about the development of medicine through the ages and across cultures”.⁷⁸ While the exhibition remained self-contained and vibrant as its own artistic entity, the context of the Wellcome Collection demonstrates a link between Baker’s at-first private creations and public advocacy regarding the normalising and awareness of mental illness.

A public talk surrounding *Diary Drawings* entitled “Bobby Baker in Conversation” made this spokeswomanship even more pronounced. During the live event, chaired by academic psychiatrist Kamaldeep Bhul, Baker firmly rebuffed an audience member’s usage of the word neurosis and engaged with another audience member who was curious about Baker’s current treatment/maintenance for mental illness while simultaneously exploring the area where

⁷⁶ Personal interview with Bobby Baker, 1 July 2008.

⁷⁷ Baker, Bobby, ‘Bobby Baker in Conversation’, *Wellcome Collection*, <<http://www.wellcomecollection.org/exhibitionsandevents/pastexhibitionsandevents/wtx053589.htm>> [accessed 1 October 2009].

⁷⁸ ‘About Us, Wellcome Collection’, *Wellcome Collection*, <<http://www.wellcomecollection.org/aboutus/index.htm>> [accessed 1 October 2009].

artists' personal lives are mounted on the wall for public display and scrutiny.⁷⁹ Baker seemingly engaged with this latter question because of an acknowledgement that interest in her current health may be an understandable outcome of the public dissemination of her work, but her rebuffing of the audience member using the term neurosis demonstrated that her engagement (much like the framing and specific curating of the drawing themselves) would be on her terms. Baker has stepped into the fray of speaking and creating about mental illness as boldly as she has for many reasons, but one is, most certainly, the hope of advancing the dialogue around mental illness in a similar way as has happened in the dialogue around cancer. While Baker's previous work dealt implicitly with issues around domesticity and feminism (*An Edible Family in a Mobile Home* (1976), *Cook Dems* (1990), *Kitchen Show* (1991)), her explicit engagement with mental illness, starting with *Pull Yourself Together*, seems like an even stronger response to a societal issue deemed worthy of discussion, especially — as I will discuss in length in Chapter 2 — as Baker engaged directly with mental illness anti-stigma campaigns and worked as a patient advocate..

Perhaps because of her explicit engagement with mental illness and because the timing of her cancer overlaps with her documented time completing the diary drawings, it seems as though a separate cancer oeuvre is unlikely to follow from Baker. Baker's performance at the Toynbee Studios, London, *F.E.A.T.* (2008), did, however, reflect on physicality and mortality, tracing her life journey through large chorus numbers and ending with the chorus members

⁷⁹ Baker, 'Bobby Baker in Conversation'. Audio available via online archive above.

covering Baker in blood-like red paint. Upon witnessing the final image, I was worried that my reading of *F.E.A.T.* demonstrated my own over-investment and/or theoretical interest in Baker's cancer. After the performance, however, many audience members commented both to myself in casual conversations and to Baker (which she later recalled to me) about the difficult, physical nature of the image. This image, however, was not unprecedented in her work, and abjection has been a strong theoretical strand in considerations of her projects (such as *Spitting Mad* (1996) or *Cook Dems* (1990)) by theorists Adrian Heathfield, Marina Warner and Michèle Barrett, each drawing on Julia Kristeva's work in "Approaching Abjection".⁸⁰ Baker explained to Heathfield that her exploration of abjection — covering herself with sauces, hitting herself with appliances — was done "always with a level of control and knowingness that for [her] is no abject".⁸¹ Baker's artistic game of cat-and-mouse around her conscious usage of abjection becomes one of its most unsettling characteristics and the characteristic most likely to promote continued thought about the images she created. The continued thought is a function of the images allowing such diverse interpretations as to being about reflections on age and gender, the visual spectacle of colour, or physical or mental illness, as I had read them.

Whether the image explicitly referred to cancer, people's immediate equation of blood with physical illness demonstrates a well-established signification system for understanding physical illness. This may also reaffirm the difficulties with creating work about mental illness, the silence it engenders

⁸⁰ Barrett and Baker, p. 13. In Barrett's introduction to *Bobby Baker: Redeeming Features of Daily Life*, she identifies how abjection is often cited as a theme by Heathfield and Warner.

⁸¹ Interview with Adrian Heathfield in Barrett and Baker, p. 142.

and the lack of language with which to discuss it. Although cancer previously had stigma and silence attached to it, Baker seems less concerned about the silences it induces in society today. Or, if the silence of physical illness were to be of a larger concern, perhaps it is because of her previous silence-breaking work on mental illness that has allowed Baker to, so fearlessly, experience cancer and allow herself to take time off and speak openly about illness as patient advocate, which I will discuss in more detail in Chapter 2.

With *Diary Drawings*, Baker demonstrates that an active non-action might just be a temporal categorisation. Although she had used her silence around mental illness in a different way than Sontag or Spence, Baker demonstrates an adept engagement with private and public display. When she was ready to share the work publicly, it entered the public realm. This idea of readiness or having-dealt-with-it-ness, presupposing a public dissemination of work, was similarly demonstrated by Jo Spence who, in a 1987 talk about her PhotoTherapy projects at the ICA in London, said:

Sharing the work at all has only been possible because, having dealt with the traumas inherent in the re-working of many memories, the work no longer has the power to upset, shock or move me. Instead of seeing myself as shameful, inferior, wrong, ugly, unloved, I now see the work and myself with different eyes.⁸²

Because Spence's photography was specifically centred around a process labelled as therapeutic, it is understandable that publication of the work was only possible after the eventual goal of healing was attained. This goal, however, is complex and aestheticised in its nature. Spence continued, "As the work progresses it becomes impossible to fulfil the expectation of narrative

⁸² Jo Spence, 'PhotoTherapy: The potential for a benevolent and healing eye?', Talk at the ICA London, December 1987, p. 4.

closure and we begin to understand that we are in the presence of an irreconcilably fragmented self".⁸³ With this statement, Spence clarifies that the endpoint she needed was not — to use a pop psychological term — to achieve closure, but to arrive at a point where she realised that all these different images (the familiar and the uncomfortable) were part of an ongoing and unending process.

It is perhaps because of this temporal condition of artistic creation that Patchett's afterword for *Autobiography of a Face* reads as opportunistic. If Grealy's "*Real*" *Story* were actually to be written, by Patchett's own admission it would demand a significant passage of time. The afterword instead reads as if someone had pushed Jo Spence to publish her PhotoTherapy projects while in progress or exhibited Bobby Baker's drawings prematurely, and without formal permission. While speaking for others has always been ethically contested territory, speaking for one so engaged in speaking for herself seems particularly ethically problematic as it is not as if she was not capable of speaking. If Grealy's experience with illness was still in a *differend* similar to Spence's, Lyotard's words hold true: "In the *differend*, something 'asks' to be put into phrases, and suffers from the wrong of not being able to be put into phrases right away".⁸⁴ The wrong, in Grealy's case, was that Patchett beat her to the punch and found the phrases for her, perhaps without permission and certainly before Grealy had attempted to create such a work herself.

In *Diary Drawings*, Baker provided a dramatic curatorial nod to the idea of readiness and public display. In the entrance to the exhibition, alongside the

⁸³ Spence, 'PhotoTherapy', p. 5.

⁸⁴ Lyotard, p. 13.

information about Baker and the process of creating the drawings sat a typical comment book where gallery visitors heaped praise on Baker's work and shared their own experience with mental illness. Behind this book, though, was a box, reminiscent of a polling box, where private commentary could be submitted. Although not stated explicitly, it is presumed that these comments would only be read by Bobby Baker or her team. The box functioned as a place where audience members could share thoughts and reflections while recognising that people may be uncomfortable expressing these thoughts publicly. Baker's acknowledgment of the comfort of others reminds the audience that this is an ongoing process for Baker as well as for us, the audience. We are welcome to be however we are, at least in theory, as no one is able to read our anonymous submission over our shoulder. In her own way, Baker is encouraging audience members to create their own active non-action through contributing to the box. Although they are not contributing to the immediate public record, there will assuredly be (or there is a presumption that there will be) an 'outing' of this work in the future, if only to Baker herself. The participation may look different than what is usually expected from gallery visitors, but uses time, anonymity and delayed disclosure as ways of expressing the process undertaken by Baker in the creation of the work.

The question of the audience's comfort level and willingness for public display harks back to a consideration of Baker's future work and whether she will write or create more explicitly about cancer, or the death of her mother, two events which feature prominently in separate sections of *Diary Drawings*. Perhaps Baker is silent about breast cancer because she has nothing to say

about it – or because she wants to continue exploring without interruption.

Perhaps there are projects she is creating about the death of her mother while being treated for breast cancer, which we will only be privy to in the future.

Beyond that, there may be an innumerable amount of life experiences about which Baker may desire to create. While the breaking of her silence has provided an opportunity to reflect about mental illness, this was only possible after she kept the work private for quite some time, demonstrating an efficacy for silence and the withholding of material from public view, at least for this extended period.

Jade, Gia and Rachel

Jade Goody died on Mothers' Day, 2009, aged 27. Goody represented the epitome of a life so highly documented that it felt oddly appropriate that her dying was documented and distributed with an equal fervour and to such a wide audience. Without documentation, it is difficult to understand Goody according to the rubric she had established for the public understanding of 'Jade Goody', an individual person extensively defined by her relationship to media. Not all individuals, however – artists, non-celebrity celebrities and non-non-celebrity celebrities – have the tools to create such documentation of their lives, nor the desire, nor the physical or emotional capacity. Their silence, or in some cases, their active non-actions, must be considered alongside those who are documenting their experiences if either is to be understood.

In recent years, the popularity of blogs and social networking sites has led to an increase in visibility or virtual visibility for people with illness, and will

be the subject of Chapter 3, *Music is Disease*. Everyday, people post information about their bodies online via Facebook, share experiences of illness via their own weblog or RealTimeCancer, instruct their friends about how best to help them via CarePages or LotsaHelpingHands and often, through continual postings and linkages, accrue fans and a community of followers engaged with their illness.⁸⁵ With an increasing number of accessible ways to make public the private experience of illness, the decision to remain silent or disconnected (either in real life or virtually) creates an even-more-deafening silence and an impression of isolation. I hope that by considering the well-conceived silences and absences of these artists and theorists, individuals — especially those with illness — can have their silence understood, appreciated and incorporated into a broader dialogue.

What I have done in this chapter is to consider these creators' silences and begin to outline some of the conditions that I see related to non-production, and the potential applications of non-production as a creative act. From a personal perspective, perhaps a theoretical or methodological understanding of active non-actions will help me fully accept the silences currently being produced by two of my friends, Gia and Rachel, each diagnosed with cancer while in their late 20s. Aside from private email communications made at the start of their treatment courses — and subsequent conversations ensuring that it was acceptable for me to write about their experiences here — Gia and Rachel have individually chosen to share little publicly or to write about their

⁸⁵'Facebook Homepage', <<http://www.facebook.com>>, 'Real Time Cancer Homepage' <<http://www.youngadultcancer.ca>>, 'CarePages Homepage' <<http://www.carepages.com>> and 'Lotsa Helping Hands Homepage' <<http://www.lotsahelpinghands.com>> [accessed on 5 November 2009]

illness as I had done with my own writing. It has been important to me not to intervene in their processes or to ask them about why, as writers and performers in their own rights, they have chosen what may be the path of creating an active non-action. This personal decision is less about being an ethical researcher and more about being a formerly-ill young adult who spent countless hours answering questions and comforting others who were upset or confused by my illness. I was comforted by Virginia Woolf's *On Being Ill* in which she confirms that it is not only contemporary sympathisers who can be difficult, saying in 1930 that "Sympathy nowadays is dispensed chiefly by the laggards and failures" and describing those most wanting to help as the ones most desperate to be thanked for helping.⁸⁶ While there may very well be an opportunity to follow up with Gia or Rachel via personal interview or the like in the future, my friendship prevents this from being pursued at this time, lest I be or appear to be selfish in my motivations.

These two women may be employing silence to signal that their experience is beyond language, or, at this moment, they have said all that they wish to say. Perhaps they wish to frame their lives pre-cancer by remaining silent. Or perhaps they are simply too tired to communicate. Perhaps this is less a question about methodology than it is a reconsideration of the position and desires of outsiders, of spectators, to the illnesses of others. Although it feels quite natural to want to hear something from them, why exactly would they share or create about their illness? To whom would any work be directed? Why do I — close friend at best, needy spectator at worst — have this desire to hear,

⁸⁶ Virginia Woolf, *On Being Ill* (New York: Hogarth Press, 1930), p. 10.

to share and to witness their illness? And finally, why do I feel like I am not alone in this desire?

When an individual experiences a bodily trauma or a diagnosis of a serious illness, the loss of language that they experience is demonstrated when in conversation with others. The ill are asked to find language when asked by others to describe their condition, are asked to draw metaphors when someone wants to hear about it. It is in this exchange that both language loss is acknowledged by the sufferer and the call of the Other — as described by Levinas — is heard by he or she that is suffering for the sufferer. It is also in this moment that a sufferer can choose an active non-action and refuse language, refuse creation and purposefully distance themselves from the process of finding language. They can also engage in a myriad of activities other than documenting or describing their lives to endless well-wishers who mean well but sap their energy. In an environment of increased interest in non-celebrity celebrity culture — including media obsessions with people like Goody and more general interest in blogs and internet connectivity — silence and isolation can seem judged as increasingly irrational approaches to living and, specifically, to experiencing illness. As frustrating as it might seem, however, to those of us with well-meaning empathy, each called to action by another's suffering, individuals must be allowed to play their cancer card, or whatever other card they are dealt, and have their silence be a response which tells us something which can be personal, powerful, political and insightful.

Chapter 2.

Perverts and Postergirls: Advocacy, Solo Performance and Propriety

Bracelet and Ribbon Advocacy

In 2004, I began to notice little yellow bracelets being worn by a handful of people working in my office in Chicago, Illinois. This occurrence seemed much like a popular book, being read by two neighbouring passengers in the same train car, but nothing more until, suddenly, they were everywhere. It wasn't until a few months into the epidemic that I was implicated in their popularity. One day, a co-worker of mine walked by my cubicle and proudly displayed a rubber bracelet adorning his wrist. "What are those things?" I blurted, completely boggled by this exhibition. It was at this moment when I learned about Lance Armstrong's LIVESTRONG Foundation and its record-breaking fundraising campaign for cancer research. I also got acquainted with the new advance in ribbon-wearing-type advocacy: rubber bracelets.

It was Whoopi Goldberg who first informed my awareness of the ubiquity of ribbon (and what would become bracelet) advocacy. While hosting the Academy Awards in 1996, Goldberg began her monologue remarking:

You don't ask a black woman to buy an expensive dress and then cover it with ribbons. I got a red ribbon for AIDS awareness. Done. I got a purple ribbon for breast cancer. Done. I got a yellow ribbon for the troops in Bosnia. Done. I got a green ribbon to free the Chinese dissidents. Done. I got a milky white ribbon for mad cow disease. Done. I got a rainbow ribbon for gay rights. Done. Done. Done again.¹

Already in 1996, there was a ribbon for everything. Although there may have been backlash from people's affiliation with the cause that the ribbon represented — thereby making the act of ribbon-wearing a politicised action in

¹ Transcript quoted in Lynn Elber, *Lakewood Ledger*, 26 March 1996, section A, p.5

many cases — the wearing of the ribbon was not, in itself, physically difficult. What Goldberg draws attention to here is the ease by which charities and advocacy groups were marketed and advertised via ribbons, but also the potential meaninglessness that an overabundance of ribbons may cause. Goldberg also identifies the tension between wanting to be politically correct and supportive of causes she believes in, and wanting to be a well-dressed woman, and in particular, a well-dressed woman of colour.

What Goldberg speaks to in 1996 was similarly explored by Danitra Vance, a comedian known for her work on the U.S. television show *Saturday Night Live*, and whose work I read only after my personal experience with cancer. Vance pointedly problematised the politics of ribbon-wearing in her 1991 performance *Live and In Colour*. Performing as a talk show host, Vance pointedly declared

If that ribbon was made out of ten pounds of steel that you had to sling over your shoulder, that might say something [...] Fifty thousand women die every year of breast cancer. Wear a ten-pound ribbon for them and one for lupus and one for diabetes and every other life-threatening, life-altering [...] That's all I have to say.²

In Vance's performance, she made it clear that the act of ribbon-wearing — because of how 'easy' it is to do, physically — highlights the tension between advocacy and action, and the potential for people to make claims for being an advocate when the action they were taking required little commitment. In 1991, Vance was assuredly also responding to the outpouring of ribbon campaigns

² Jo Bonney, *Extreme Exposure: An Anthology of Solo Performance Texts from the Twentieth Century* (New York: TCG Press), p. 192.

which developed at such rapid rate that 1992 was dubbed by *The New York Times* as “The Year of The Ribbon”.³

Thinking back to the yellow bracelet, and how its wearer had so proudly showed it off to me, I began considering what the wearing of this man’s bracelet was telling me about his commitment to cancer research and issues of survivorship. Had he been a fundraiser — more than paying \$1 for the bracelet? Was he himself a cancer survivor? Was he trying to make a safe space for people to speak about their experiences with illness? Was he just a huge fan of Lance Armstrong? The showing off of the bracelet made me reconsider what is actually being said by the wearer, or if the wearing of a bracelet was a mixture between advocacy and fashion. And if it was advocacy and fashion mixed together, which one was more important? And why did I care so much?

It was Vance’s strong rebuke of ribbon-wearing advocacy, which, upon learning of the LIVESTRONG campaign, made me bristle with discomfort. Yes, money was being directed towards cancer research — lots of money — and a public dialogue was being started around cancer, survivorship and the politics of cancer funding. And yet, there was something which reminded me of the relatively low level of commitment needed to participate in online petitions, or worse, the desire to make a fashion statement which — much like the (RED) campaign — blended commercial purchases with activism and corporate PR campaigns with grassroots advocacy. (RED), an initiative fronted by U2 lead singer Bono in 2006, enlists corporations to create a series of (RED) products, the full proceeds of which are donated to the Global Fund, the world’s “leading

³ Jesse Green, ‘The Year of the Ribbon’, *The New York Times*, 3 May 1992, <<http://www.nytimes.com/1992/05/03/style/the-year-of-the-ribbon.html?pagewanted=all&src=pm>> [accessed 25 January 2012].

financier of programs to fight AIDS, TB and malaria".⁴ While (RED) advocates cite that 160,000 orphans in Africa have received treatment through Global Fund programmes, it is (RED)'s explicit relationship with consumerism that has raised the most (red) flags, as noted by, among others, columnist Paul Vallely.⁵ While press enunciated the tension between branding, popularity and fundraising for medical research and treatment, others noted how the press generated by the campaign produced meagre financial intakes (around \$18million while costing \$100million to produce) and had demonstrable impacts on smaller, more efficient non-profits working in the sector.⁶

A complete history of ribbon activism is chronicled by Sandy M. Fernandez who wrote on issues similar to those seen by Vallely (above) in relationship to the development of the pink ribbon and breast cancer 'awareness', and its relationship to the marketing departments of Avon and Estée Lauder Cosmetics. Writing in the now-defunct *MAMM Magazine* in 1998, Fernandez incorrectly predicted the demise of the pink ribbon, but correctly noted a tension — which will be the focus of this chapter — between individuals and groups who were purported to be working on the same 'cause' but maintained different approaches.⁷ For Charlotte Haley — the woman who founded the peach-coloured breast cancer awareness ribbon — that conflict was with the commercial interests of cosmetic companies in the early 90s, a

⁴ 'The (RED) Idea', <<http://www.joinred.com/aboutred>> [accessed 17 May 2010].

⁵ Paul Vallely, 'The Big Question: Does the Red Campaign Help Big Western Brands More Than Africa', *The Independent*, 9 March 2007, <<http://www.independent.co.uk/news/world/politics/the-big-question-does-the-red-campaign-help-big-western-brands-more-than-africa-439425.html>> [accessed 17 May 2010].

⁶ Mya Frazier, 'Costly Red Campaign Reaps Meager \$18 Million', *Advertising Age*, 5 March 2007, <http://adage.com/article?article_id=115287> [accessed 17 May 2010].

⁷ Sally M. Fernandez, 'Pretty in Pink', originally printed in *MAMM Magazine*, June/July 1998, and available at *Think Before You Pink*, <http://thinkbeforeyoupink.org/?page_id=26> [accessed 29 January 2012].

conflict of interest so irreconcilable that the pink ribbon was founded by cosmetic companies to avoid working with Haley. The examples I hope to employ in this chapter will not be exclusively adversarial — in fact, with Bobby Baker’s work, exactly the opposite — but I do mean to highlight these separations between individuals and organisations and to employ theory by Miranda Joseph and Barbara Ehrenreich to demonstrate the dangerous collapsing of community identities.

This chapter will explore what is at stake when artists, creating performance work about illness, are in complicated relationships with advocacy-led organisations, funding bodies and people who may have investment in the tenor of a conversation. I will look specifically at the relationships between Rita Marcalo and Epilepsy Action and Bobby Baker and the Wellcome Collection, demonstrating various pitfalls and opportunities that such interactions present. I will use a discussion of Bob Flanagan’s work with Cystic Fibrosis Summer Camp and with the Make-a-Wish Foundation to demonstrate how the relationships between advocacy organisations and artists may exemplify deeply held understandings of how one’s identity — especially for people with illness — may be policed by organisations and an artist’s presumptions about the organisations’ expectations. While the imagined or perceived audience was relevant to the development of my performance *Other Funny Stories About Cancer*, which I will talk about in more depth in this chapter, there are organisations and artists with more at stake.

In relation to issues of spectatorship, this chapter will explore how one’s performance of illness can be deeply policed territory, and will examine how those who ‘mis-perform’ their illness may suffer unexpected consequences, while others develop strategies to address this alleged policing. I will investigate

this mis-performance of illness using the lens of Wolfgang Iser and his work on the *implied reader*, which I will reconfigure into *implied spectator*. By demonstrating how artists and organisations push against established narratives of the illnesses and disabilities about which they are creating/advocating, I will demonstrate an imperative for these individuals and groups to strategise around how people have been conditioned to read/view potential actions dealing with these illnesses and disabilities.

Relationships between artists and ‘the cause’ have long been considered by many including Stuart Hall and his work on the ‘burden of representation’, but it is Douglas Crimp’s work on the development of an HIV/AIDS activist aesthetic which will be most influential for my analysis.⁸ Crimp’s collection *AIDS: Cultural Analysis, Cultural Activism* and, in particular, his reading of ACT UP’s *Let the Record Show...* (1987), carefully highlight what is at stake in an art work which is engaged in explicit advocacy and whose advocacy is more than just raising money for ‘the cause’. ACT UP’s *Let the Record Show...* was an installation in the window of New York’s New Museum of Contemporary Art in 1987 which juxtaposed facts about rates of infection and death with quotations from the epidemic’s most stalwart deniers, and mixed images of Nuremberg war criminals and these ‘AIDS criminals’ responsible for the quotations.⁹ The most striking feature of the installation was the now-iconic neon image above the black and white photo mural, boldly proclaiming the equation SILENCE = DEATH. In his reading of *Let the Record Show...* Crimp

⁸ David Morley and Kuan-Hsing Chen, eds., *Stuart Hall: Critical Dialogues in Cultural Studies* (New York: Routledge, 1996), p. 442.

⁹ Douglas Crimp, ‘AIDS: Cultural Analysis/Cultural Activism’, *AIDS: Cultural Analysis/Cultural Activism* (Cambridge, Massachusetts: MIT Press, 1987), p. 7.

analyses the work's importance to the group of ACT UP members who created the work:

these [artistic] practices are employed by the collectives' members as an essential part of their AIDS activism. This is not to say that the individuals involved are not artists in the more conventional sense of the word; many of these people work within the precincts of the traditional art world and its institutions. But involvement in the AIDS crisis has not left their relation to the world unaltered.¹⁰

This work demonstrates that the cultural issues surrounding HIV/AIDS *were* the issue, and drew a direct line to the hypocrisy in the US government — and the Reagan administration in particular — and in media (who traded on cultural biases and fear-mongering to justify improper attention to the epidemic) to the mismanagement of the crisis and the countless preventable deaths. For the members of ACT UP, who arose out of a particular moment and with a written, explicit agenda (using “direct action to end the AIDS crisis”, a slogan which they still maintain today)¹¹, the term awareness was employed in relation to *Let the Record Show...* in a forceful way; they believed that people's ignorance around politicians' hypocrisy was in direct correlation to the number of people who were dying of AIDS.¹² The awareness they espoused was extremely pointed; instead of speaking through anti-stigma campaigns (as I will discuss in relation to mental illness and epilepsy) which have no specifically-named offenders but target broad public attitudes, artists and other members from ACT UP were interested in naming and shaming the government officials who they deemed most destructive through raising awareness of their actions.

‘Awareness’, as a term, continues to be bandied about, and while it is an important concept, it has, as I hope to demonstrate, sometimes been turned

¹⁰ Crimp, p. 12.

¹¹ ‘ACT UP Homepage’, *ACT UP/NY*, <<http://www.actupny.org/>> [accessed 30 January 2012].

¹² Crimp, p. 7.

into a meaningless moniker which incorporates everything, nothing, or whatever is convenient. Barbara Brenner, executive director of Breast Cancer Awareness elucidated the potential of this point very clearly when she stated in 1997:

“There is a value to awareness, but awareness of what, and to what end?”¹³

While a lack of awareness surrounding breast cancer or mental illness or epilepsy (which I’ll use as case studies in this chapter) may discourage people from preventative care, seeking help or shame people into having seizures in private where they cannot be assisted, the tone of the awareness campaigns associated with mental illness and epilepsy lack the same political fire as those associated with HIV/AIDS, especially in the 80s and 90s. Perhaps this is because such outrage and political fire is less fashionable, artistically, or deemed less effective, politically, today. Or perhaps because they are slower growing movements, whereas the HIV/AIDS activism, which Crimp discusses, was of a distinct time and place and newness, and epilepsy and mental health activist do not have a similarly focused base or community to deploy. Breast cancer — and cancer in general — is different than mental illness or epilepsy in this regard, in that the 80s and 90s saw a major moment of pointed political activism from cancer activists who (as Mukherjee chronicles in *The Emperor of All Maladies*) were inspired by ACT UP’s chants of ‘Drugs into bodies; drugs into bodies’ to insist on easier access to chemotherapy and an end to extensive double-blind studies.¹⁴

The softer tone of mental health and epilepsy groups may also have to do with the potential for quantifiability of the awareness that these campaigns espouse. For ACT UP, a clear result of their advocacy could be quantified if

¹³ Fernandez, ‘Pretty in Pink’.

¹⁴ Siddhartha Mukherjee, *The Emperor of All Maladies* (London: Fourth Estate, 2011), p. 319.

drug treatments were more widely available, comprehensive and effective, or more funding went into developing antiretrovirals. While the efforts to end stigma and increase public dialogue about mental illness are quantifiable from the angle of the producers of the information — how many posters are made, how many curricula put in place — attitude adjustments are notoriously harder to follow and identify. The audience of these campaigns is also harder to quantify. The anti-stigma campaigns are not directed towards an ‘enemy’ (like the politicians featured in *Let the Record Show...*) but rather focused on normalising representation of stigmatised groups as they are seen by the entire population.

i[2]y and the Angry Parents

While ribbons have been mostly relegated to HIV/AIDS and breast cancer awareness, rubber bracelets have become the most ubiquitous form of fundraising accessory. Rubber bracelets are now sold on behalf of autism awareness, stopping domestic violence, helping orphans in Africa and as many other causes as there are colours.¹⁵ It is perhaps in response to this ubiquity that the New York-based patient advocacy foundation i[2]y (I’m Too Young For This!) marketed its own bracelet-selling fundraiser with the tag-line “It’s your other wristband’s new best friend,” which recognises that many people with cancer may — or probably will — be wearing a LIVESTRONG, or similar, bracelet.¹⁶ Always marketing itself as an organisation virulently against

¹⁵ ‘Autism Awareness’, *Autism Awareness UK*, <<http://www.autismawarenessuk.com/>> [accessed 22 January 2012], ‘Domestic Violence Wristbands’, *Shanrene Jewelry and Gift Store* <<http://www.shanrene.com/page/001/PROD/domestic-violence-wristband>> [accessed 22 January 2012], ‘Silicone Wristbands’, *LIV Village*, <<http://www.liv-village.com/blog/tag/silicone-wristbands/>> [accessed 22 January 2012].

¹⁶ ‘Stupid Cancer Bracelets’, *Stupid Cancer Bracelets*, <<http://stupidcancerbracelets.blogspot.com/>> [accessed 22 January 2012]. It should be noted that this is not on the I’m Too Young For This! Foundation’s official website and the spelling is the original.

traditional cancer fundraising like that of the much-larger Susan G. Komen Foundation, i[2]y's fundraising campaign engages with the popular fashion accessory of the bracelet while attempting to subvert its meaning and alert bracelet wearers to the politics of their own participation. The i[2]y bracelet is black with the only writing being their web address ("stupidcancer.com") and a stark drawing of a white hand putting up its middle finger. Cheekily meant to "Give Cancer the Bird" the marketing of the bracelets demonstrate an awareness of the ubiquity of bracelet advocacy and provide a means for i[2]y to raise money through a deployment of current fads.¹⁷

Unfortunately for i[2]y, engagement with a fad and a simultaneous critique of that fad led to an unexpected conflict in 2010. From an email sent by Matthew Zachary (founder and predominant voice of i[2]y), one can almost hear the irate phone calls which inspired Zachary's response:

After having too many mothers asking for their \$\$ back when their overly-enthusiastic tween bought a 50 pack to hand out at church, we've listened to your feedback and are thrilled to announce a family friendly version featuring "Kemo", the stupid cancer birdie mascot... We're happy to stir the pot so long as we're not just raising awareness that young adults can and do get cancer but taking real action to give voice to the next generation of survivors and co-survivors who truly need it.¹⁸

While i[2]y does not define itself as an arts organisation, instead being resoundingly organised around patient advocacy, its negotiations with representation and media demonstrate an adept employment of media critique common in the practice of many artists and interventionists, such as *Adbusters* or Reverend Billy. As exemplified by the email above, the pressure on Zachary

¹⁷ 'Stupid Cancer Merch Store', <<http://www.cafepress.com/stupidcancer/8366699>> [accessed 20 January 2012]. The official I'm Too Young for This! Cancer Foundation no longer sells the bracelet as of 2011, but has released an extensive line of bird-themed products. This online vendor is the official vendor of i[2]y today.

¹⁸ Matthew Zachary, email to i[2]y's mailing list, 19 January 2010.

to accommodate young adults who were originally unconsidered by the campaign was strong, or at least strong enough to find a compromise. Although their target audience for the campaign was, presumably, young adults with cancer, i[2]y failed to realise that the access by young adults to the campaign (by buying bracelets online) was more than likely going to require the approval of an adult, an adult who might not want their child to be handing out bracelets with church- or school-unfriendly symbolism on them at church or school.

Zachary's compromise accommodates multiple comfort levels, as much about how parents allow their children to behave as about how parents and children (with or without cancer) discuss illness. Although Zachary fails to take a hard-line stance against adult censorship of children or teenagers in this case, this also seems out of his and i[2]y's remit. The example of i[2]y and their negotiations with their fundraising and advocacy campaigns demonstrate an occasion when a creative and artistic impulse comes into tension with the audience — or perceived audience — and their expectations regarding the tenor of a particular conversation. This phenomenon is striking in relation to cancer, where the majority of the conversation continues to be dominated with family-friendly imagery such as Make-A-Wish angels, breast cancer pink ribbons or Lance Armstrong's signature yellow LIVESTRONG bracelets.

Cancer and Policed Positivity

In her 2009 book *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America*, Barbara Ehrenreich chronicles her own experience with breast cancer and the tone with which the disease is discussed. "I noticed for the first time", she writes about diagnosis

an assumption about who I am, where I am going, and what I will need when I get there. Almost all of the eye-level space [in the

breast cancer clinic changing room] had been filled with photocopied bits of cuteness and sentimentality.¹⁹

Ehrenreich's 'Smile or Die' chapter most clearly provides evidence of the policing of positivity in conversations about cancer, which she does while strongly rebuking disproved studies about the relationship between these positive attitudes and survival rates. Even without a consideration of the privileging of survivors over those who die from the disease or the disturbing trend of people selling cancer as a not-to-be-missed life experience, Ehrenreich documents not only the cult of positivity around cancer and treatment, but the extreme protection of that tone by those active inside the cancer community — an ambiguous, and yet, powerful grouping of people. After placing a negatively-toned posting on an online support network, Ehrenreich received vicious replies including “I really dislike saying you have a bad attitude towards all of this, but you do, and it’s not going to help you in the least” and “You need to run, not walk, to some counselling...”²⁰ While the posts’ authors frame their criticism of Ehrenreich’s attitude in a this-is-for-your-own-good context, the comments clearly demonstrate discomfort with any cancer patient’s attitude being anything other than cheerful, strong and positive. Concurrent with their engagement with the website, individual cancer patients are pitted against the (in this case, virtual) community and monitored for their attitude. Although there are notable exceptions to the American-style positivity around survival in both the United States and United Kingdom (Ehrenreich’s examples mark this positivity as a particularly American phenomenon), the equating of happiness to healthiness continues to prevail. This entrenched attitude, however, might be impossible to

¹⁹ Barbara Ehrenreich, *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America* (New York: Metropolitan Books, 2009), p.16.

²⁰ Ehrenreich, p. 32.

excise, as the number of people benefiting from it will always largely outnumber those for whom it is problematic. As Ehrenreich writes, “[Cheeriness] is a great convenience for health workers and even friends of the afflicted, who might prefer fake cheer to complaining, but it is not so easy on the afflicted.”²¹

An awareness around the pressure to craft a cheery and inspiring tone when discussing cancer was the point of departure for my own writing *Other Funny Stories About Cancer*, written and performed in 2006. As a 22-year-old cancer survivor, the writing of my first ‘cancer play’ (*BALL*, 2003) strove to tell my journey from testicular cancer diagnosis, through surgeries and chemotherapy, and finally to survival.²² The trajectory of the work felt quite standard, with a clear antagonist (cancer), clear narrative structure (from sickness to health) and a triumphant and dare-I-say, inspiring ending. There was a strong pressure, however, also to keep that trajectory more-or-less in place and to keep the work tidy and appropriate for family viewing. By family viewing I mean appropriate for Lobel family viewing — I knew they would inevitably see the work and I was happy to make a performance that I could share with them. While I knew that others audiences of my peers would see the work, in the consideration of my audience when creating the work it was that potential audience of my family that most informed my writing. Years of living with my relatively-conservative family made me keep in mind what would and would not shock or offend, although with testicular cancer being the illness in question, it was necessarily impossible to keep all jokes from hitting below the belt.

²¹ Ehrenreich, p. 41.

²² Brian Lobel, ‘BALL’, *Text & Performance Quarterly*, 28, 1/2, 2008, pp. 160-177.

But beyond considering the reactions of my family to *BALL*, there felt a greater pressure to conform to some kind of understandable cancer narrative. Understandable to whom became the question. Who was this perceived audience who would judge me? How would their judgement affect my livelihood or my performance making? With these questions, I began to write *Other Funny Stories About Cancer*, which questioned the ideas of propriety in illness and the necessity to speak to a cancer crowd in certain tone.²³ Written in 2005, the hour-long monologue performance premiered at the Live Bait Theatre in Chicago in 2006, and was directed by Margot Bordelon. The text of the performance begins only after a cigarette is lit and smoked:

The first cancer play had all the necessary beautiful parts – diagnosis, chemotherapy, sadness, despair, redemption. I did, however, leave out some of the more uncomfortable parts: hooking up with my then-48-year-old Cuban male lover, Rolando, during my chemotherapy, coming out to my mother the day I had my right testicle removed, how my cancer was originally misdiagnosed because my shit doctor thought that I was just freaking out over having unprotected oral sex with other men... You probably can't envision any of those three stories in an after-school special about cancer, nor could I, which is presumably why I left them out. Trashy stories about faggotry and STDs belied my cancer's purity and distracted people from my inspiring journey to survival.²⁴

Other Funny Stories About Cancer took expectations of propriety when speaking about illness as its starting point and was influenced by issues of internalised homophobia. Through direct address and casual revelations ("Do you want to hear [this story]? Good, because I'm going to tell it") audience members were treated as both people with 'normal' expectations (wanting pure and inspirational cancer stories) and allies who could handle the truth, warts

²³ Lobel, Brian, *BALL & Other Funny Stories About Cancer* (London: Oberon, 2012), pp. 15-16.

²⁴ Lobel, p. 55.

and all. If they were not allies who could handle the truth, however, the venue was small and audience members could easily walk out.

What was at stake inside *Other Funny Stories About Cancer* was metaphysical and emotional — perhaps the audience would not like the work or not appreciate the opinions shared — but there were no financial stakes such as present in i[2]y's fundraiser. Had people disagreed with me, I would not have had the irate phone calls that Zachary received, as the producing theatre's press department was not expansive enough to draw either positive or negative press attention to the work. Although the lack of a media presence was frustrating as a young performer, it also allowed the performance space to be a space for me to explore the territory between propriety and work about illness. Because the work had no stated goals regarding advocacy, nor did it receive any sort of funding, the only interested parties (and those with any control over the work's development) were myself, director Bordelon, and Live Bait. My unintentional disengagement with medical or cancer contexts allowed themes of propriety to be explored in *Other Funny Stories About Cancer* without practical implications — a luxury which is not afforded to the case studies presented here. While performers like Marcalo embraced the controversy, Baker used an avoidance of controversy as a steering point for her production, as I'll explore. Others, like Bob Flanagan and Sheree Rose, responded to tensions between their own work and broader medical narratives by featuring that tension as a central informing force.

Bob Flanagan, Sheree Rose and the Implied Spectator

As a widely-respected artist working with a body-based practice, Bob Flanagan's sadomasochistic performances, his lived experience of being a man with cystic fibrosis and how his body brings to the forefront how spectators understand embodied experience have been discussed by Amelia Jones, Lynda Hart and many more²⁵. In *The Scar of Visibility*, Petra Kupperts discusses Bob Flanagan and partner/co-performance-maker Sheree Rose's collaborative process and how Sheree Rose's normative body informs their work together. But before Kupperts interrogates this, she outlines Flanagan's relationship to sentimentality, a trope often employed in disability and illness discourses, and one explored in Rosemarie Garland-Thomson's readings of the work of historic freak shows during Victorian America.²⁶ Kupperts' discussion of sentimentality explores what might be at stake in a sentimental register being applied to people with disabilities, at least from an historical context:

Victorian pity is the core affect engendered by a sentimental approach to physical or economic otherness. The pity creates a seesaw effect: lowering the other while lifting the self, as two different forms of embodiment are evaluated and set in relation to one another. The viewer can indulge in his or her own social status in the performance of difference. Thus, the object of sentimental performance is not to see the other, but to put the self on display in its finery, its appropriate emotion, its performance of social codes that reinforce its social position.²⁷

²⁵ Amelia Jones, *Body Art: Performing the Subject* (Minneapolis and London: University of Minnesota Press, 1998), p.226-238 and Lynda Hart, *Between the Body and the Flesh: Performing Sadomasochism* (New York: Columbia University Press, 1998).

²⁶ Rosemarie Garland-Thomson, 'Narratives of Deviance and Delight: Staring at Julia Pastrana, the 'Extraordinary Lady'', *Beyond the Binary: Reconstructing Cultural Identity in a Multicultural Context*, ed. Timothy B. Powell (London: Rutgers University Press, 1999), p. 100.

²⁷ Petra Kupperts, *The Scar of Visibility: Medical Performances and Contemporary Art* (Minneapolis and London: University of Minnesota Press, 2007), p. 80.

While the reinforcement of the social position of the privileged may not be the only rationale for why a certain register, which some might call sentimental, continues to be enforced in relation to illness and disability, it is necessary to keep such a critique in mind. This is because Koppers' critique highlights that charities and organisations seemingly 'in the service of' others may be engaging in a politic in which they lower the status of others through pity. The lowering of this status, therefore, allows more-normative experiences to be lifted and reified. Necessarily considered on a case-by-case basis, watching for this seesawing relationship (pity/down, normalised experience/up) is an essential concept which Koppers introduces and which clearly frames my own perceptions about cancer and other fundraising.

In addition to her critique on the seesaw of pity and normativity, Koppers also usefully highlights Bob Flanagan's multiple roles as fundraiser and advocate for cystic fibrosis organisations, poet, sadomasochist and provocateur, each of which is present in Kirby Dick's documentary *Sick: The Life & Death of Bob Flanagan, Supermasochist* (1997) and which demonstrate a pointed incursion into the world of propriety and advocacy. What I will add to Koppers' discussion of Flanagan is a demonstration that his relationship to organisations and advocacy significantly recognised — as part of its ontology — the outside eye of the advocacy organisation and treated this presumed audience with both care and humour. In *Sick*, many examples demonstrate sentimentality — or a history of sentimentality — as it relates to illness narratives: from the quiet moments in the hospital (when Flanagan is blessed by a well-meaning, if slightly-too-forceful, nurse), to the moment when a woman addresses Flanagan during his New Museum exhibition, saying "I don't like this" as if offended by

his work's non-sentimentality.²⁸ In the latter example, the policing of sentimentality — or at least a discomfort with Flanagan's mixing of the 'profane' and the otherwise 'pitiable' — is clearly demonstrated.

When documenting Flanagan's relationship with what I'll call explicit advocacy, *Sick* employs a less ironic tone. Explicit advocacy describes the moment when a performer consciously and statedly engages with a 'cause' or an organisation founded around a 'cause' which has social, usually philanthropic but not necessarily artistic, goals as central to their mission statement. By adding 'explicit', I hope to clarify that while many performances have, as their mission, a desire to advocate for a 'cause' as part of the overall goals of their work, with these moments of explicit advocacy, the 'cause' is the most foregrounded, if not the only, feature. Although I hope to show that these relationships can be complicated, it is important to locate where artists and performers are working with explicit advocacy as it may affect the work produced and how the work should be/could be read.

As a summer camp counsellor at Cystic Fibrosis Summer Camp, Flanagan is shown in *Sick* singing two songs around a camp-fire. Flanagan worked at the summer camp for 21 years between 1973 and 1995 as a "director, assistant director and all around camp fool".²⁹ The first song is a fable about an imaginary girlfriend, a farmer (pharm-er) named Ivy (I.V.), and the second song a cover of Rod Stewart's *Forever Young* renamed as *Forever Lung*. Adoring campers — including children — cheer and laugh with Flanagan's lyrics, recognising common themes about mucous and chest beating, and Flanagan appears to enjoy his interaction with the community.

²⁸ *Sick*, dir. by Kirby Dick (Lionsgate, 1997).

²⁹ Bob Flanagan, *Supermasochist* (San Francisco: Re/Search Publications, 1993), p. 10.

While *Sick* does not show Flanagan speaking directly about his relationship to the camp, as the film is edited, it can be read that in this moment, he is giving himself as a role model and leader for, presumably, little financial remuneration or artistic attention. The goal of similar summer camps, or the narrative generally told about such camps, is to be a place for kids with cystic fibrosis to share their experience and have fun in a safe environment, with counsellors generously aiding the pursuit of this goal.³⁰

What is missing in *Sick* is Flanagan's more complicated and personal history with the Cystic Fibrosis Summer Camp, which although never thoroughly documented in his writings, makes a few appearances in his infamous publication *Fuck Journal*.³¹ In *Fuck Journal*, Flanagan describes each time he has sex over a one-year period. The tone of *Fuck Journal* is decidedly sparse and direct, with individual entries terse, such as "Slow fuck in the morning" and although the entire book challenges ideas of sentimentality as it relates to ill bodies, his entries about Cystic Fibrosis Summer Camp seem exceptional in their honesty.³² He writes:

[Sheree] visits me at my summer camp job. After lunch we go to the lodge, take our clothes off, and fuck. A quick one because we have to get to the pool. / Fucking again at camp, in the ranch house. On top of someone's 'Peanuts' blanket and Snoopy pillow. Clothes off. Pants to my knees. I eat her. We fuck and it's great, her on top.³³

While the entries written in 1987 and the documentary from 1995 demonstrate Flanagan at different stages in his maturity and health, *Sick's* earnestness around the camp reaffirm a holiness around Flanagan's work with advocacy,

³⁰ See, for example, 'Camps', *Cystic-L*, <http://cystic-l.org/handbook/html/cf_camps.htm> [accessed 16 May 2010].

³¹ Bob Flanagan, *Fuck Journal* (New York: Hanuman Press, 1987).

³² Flanagan, *Fuck Journal*, p. 19.

³³ Flanagan, *Fuck Journal*, p. 59.

and perhaps a policing of tone around advocacy-related work. His work, in that moment, was about being a role model to kids, and it appears (at least from the documentary's edits) that he was appropriately inspiring.

This idea of 'proper' role modelling resonates with my work in *Other Funny Stories About Cancer*. Alongside the removed, allegedly inappropriate narrative about cancer, in this play I included a narrative about being a queer camp counsellor at Seeds of Peace International Camp, a co-existence program for teenage students from the Middle East and South Asia. The narrative about Seeds of Peace — at least from a public relations perspective — was always about Palestinian and Israeli friendships, of youth empowerment and not about the sexuality of the staff members.³⁴ But these elements did exist side-by-side:

I feel guilty for writing [these stories of queerness and masturbation at Seeds of Peace Camp], but more so, I feel guilty for even experiencing them. Cancer should be a neutered struggle against an unethical malignancy. Seeds of Peace should be about youth empowerment and interpersonal, as well as international, coexistence. Maybe I should just keep talking about my work with youth or beating cancer, not beating off, Seeds of Peace, not spreading my seed. Just ignore all of this, the messy parts I mean, and just look at the pure stuff, the good stuff, the inspirational stuff. Isn't it beautiful? Cancer survivor-turned-mentor-for-the-youth-of-the-Middle East. That's me.³⁵

The relationship between advocacy and propriety relates to issues (causes) outside of health and international co-existence, but whether or not they are about these issues, performance and creative work can, though, in their diverse forms, allow an individual to draw literal attention to what they would like an audience to see and the narrative they would like an audience to experience. As

³⁴ 'About Seeds of Peace', *Seeds of Peace*, <<http://seedsofpeace.org/about>> [accessed 22 January 2012].

³⁵ Lobel, pp. 75-76..

a solo performer, I attempted to draw audience attention to my conflict between propriety and illness with text in the form of a theatrical performance.

Although Bob Flanagan did not bring the two worlds — summer camp work and his sex life — together in the same venue, *Sick* and *Fuck Journal* can now be read as two parts of a finite collection of Flanagan's life works. Although a complete understanding of Flanagan's opinions and artistic goals is impossible, individual pieces can be considered side-by-side and scrutinised for more complex and complicated relationships. Wrapped up in and wrapping up these relationships is the reality of how judgements are placed on sick or otherwise non-normative bodies by both the general public and those that are responsible for framing stories about them (as Kirby Dick was with *Sick*). These judgements most often come in the form of patronising sentiment towards those with non-normative bodies and assumptions about how their story should best be told, for the benefit of that 'general public'. As Ehrenreich writes, "I didn't mind dying [of breast cancer], but the idea that I should do so while clutching a teddy and with a sweet little smile on my face — well, no amount of philosophy had prepared me for that."³⁶

Beyond this discourse about sentimentality being imposed by a 'general public', *Sick* demonstrates a relationship between the ill body and imagined or perceived sentimentality policed by people with illness themselves. For example, the documentary shows a 19-year old woman is sitting topless at a piercing studio, holding Flanagan's hand as she gets her left nipple pierced. This woman, Sara, had met Flanagan through the Make-A-Wish Foundation, which had granted her wish to meet Bob Flanagan the previous year. The documentary and excerpts from Flanagan's *Pain Journal* demonstrate an

³⁶ Ehrenreich, p. 17.

interesting and ambiguous relationship between Bob and Sara and Sheree (Sheree believing that Sara wanted to have sex with Bob, and Bob not necessarily denying that this would not be a good idea) but at this moment, all three are laughing heartily in preparation for the piercing.³⁷ It is now when, seemingly unprompted, Sara turns to the camera and shouts “I made a Wish and look what happened!” As a single moment in a documentary, this laughed line shows a connection and sense of togetherness around both sadomasochistic practices and cystic fibrosis, and to the history that the three people share. More than this, though, Sara’s invocation of the Make-A-Wish Foundation at the moment of nipple piercing might demonstrate a preoccupation with sentimentality, self-policing and correct modes of being. Such self-policing draws attention not only to how those with non-normative bodies are watched by others, but to how they perceive to be watched and policed at all times. If those with non-normative bodies do not feel policed at all times, the scene demonstrates that they may feel this way at times when they are breaking some sort of conventionalised norm. The conventionalised norm, in this case — as Sara describes elsewhere in *Sick* — is that people with CF are feeble and inactive.

The Mission Statement of Make-A-Wish Canada — although they met in California, Sara was Canadian — is “to grant the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength and joy”.³⁸ This is a statement which quickly conjures a specific attitude around illness which is both positive and affirming. While Make-A-Wish has clearly produced atypical wishes in the past (Sara meeting Flanagan as

³⁷ Bob Flanagan, *The Pain Journal* (Los Angeles: Semiotext(e)/Smart Art Press, 2000).

³⁸ ‘Our Mission’, *Make-a-Wish Canada*, <http://www.makeawish.ca/about_us/our_mission> [accessed 30 April 2010].

one such wish), the majority of wishes involve meeting celebrities and family trips to Disneyworld or the Olympics. The Wishes are broken down on the Make-A-Wish website between the categories Travel Wishes, Adventure Wishes, Entertainment and Fantasy Wishes, and Celebrity Wishes, although most celebrities include non-controversial figures such as Justin Bieber or Dora the Explorer.³⁹ Given that the majority of wishes are for younger children, and that they are experiences designed for both sick children and parents, the family-friendly nature of the events is not surprising. What is surprising, however, is that, one year after having her Make-A-Wish granted, with no Make-A-Wish officials present, and on a journey of her own planning, Sara invokes the foundation at the moment immediately before the piercing. Sara, in doing so, projects the disapproval of an audience (the audience watching the documentary) who is not present, figuratively or literally, in the room. In this brief moment, the disapproving audience becomes a literal body in Sara's mind, chiding Sara for 'being bad'. Not only does Sara recognise that audience, and their expectations, but Flanagan and Sheree Rose laugh heartily along in recognition, as if the Cystic Fibrosis/Make-A-Wish Code of Conduct was emblazoned somewhere in the piercing studio, with Sara being clearly in violation of its terms.

Sara, Flanagan and Rose's actions in the piercing parlour demonstrate more than a simple projection of the expectations placed on to non-normative bodies. They are doing more than reiterating judgements presumably placed on their bodies by other people in the room. They are hinting at the continued role that the Make-A-Wish Foundation had in bringing them together and acknowledging the omnipresent eye of the non-profit world, of the fundraising

³⁹ 'Celebrity Wishes', *Make-a-Wish Canada*, <http://www.makeawish.ca/wish_stories/celebrity_wishes> [accessed 5 February 2012].

world, of the world which polices propriety. The policing, although difficult to quantify, felt to me — both during and after being ill with cancer — an inescapable reality with its origins embedded in people’s discomfort with illness and difference more generally. This discomfort gets placated, in part, by organisations like the Make-A-Wish Foundation. Such an organisation reaffirms an expectant tone around illness through their press materials and usual wishes granted, while simultaneously dominating the discussion and making other tones or narratives about illness feel aberrant. This scene might encapsulate such a consciousness of aberrance had by Flanagan — the feeling of being on the other side of the normative one-directional gaze (as opposed to the multi-dimensional stare as described by Garland-Thomson) which other people with cystic fibrosis or other illnesses or disabilities might share. On Flanagan’s side of the gaze, being a person with a condition for which people raise funds, organise and/or campaign might mean a relationship or at least connection with advocacy at all times — of being an ideal patient or a role model for all people.

The pressure to act as role model or the awareness around the beliefs and judgements of other people are not often considered insurmountable impediments in the world, and may be shared (and responded to) by members of many other groups of people. When considered in a performance context, though, there is a relationship between creator/performer and receiver/audience which makes this a moment to consider how work can be created for given audiences and the importance of audiences in making meaning in art and performance. Wolfgang Iser wrote of the phenomenon of understanding an audience’s impression of a work through their participation (prefigured by the creator of that work) in *The Implied Reader*. The term ‘implied reader’, Iser writes,

incorporates both the pre-structuring of the potential meaning by the text, and the reader's actualisation of this potential through the reading process. It refers to the active nature of this process — which will vary historically from one age to another.⁴⁰

Considering *Sick* in the context of Iser's implied reader — rejigging to become implied spectator — allows for an understanding of these social identities as an active part of the work creation process. In the scene in the piercing parlour, Flanagan and Sara keep an eye on their imaginary, implied spectators, apologise to them for breaking the propriety or sentimentality that people have come to expect around illness, while the spectator, simultaneously, configures his or herself around Flanagan's projected opinion about us — we know exactly what this scene means in relation to judgements placed on ill bodies.

The implied spectator may be directly related to Garland-Thomson's work on the starrer/staree, discussed previously, as both are dependent on expectation, distance and a relationship built on either participant presupposing the other participant's actions. Garland-Thomson's work in *Staring* describes hard-won moments of parity between people on both side of the stare, yet — as I discuss in the Introduction — the work may fail to provide space for those for whom parity is not a goal, or who will always be on the receiving end of a disempowering stare. If however, the stare can be thought of in relationship to the implied reader or spectator — implied starrer, perhaps? — Garland-Thomson and Iser's work can be brought together to recognise that, as with the implied reader, the person creating a work has a particular audience in mind, and with the starrer/staree, there is a possibility that the creator and the created-for share common ground, no matter how virtual, imaginary or distant their relationship. Although I will be using the term implied spectator to describe the process by

⁴⁰ Wolfgang Iser, *The Implied Reader: Patterns of Communication in Prose Fiction from Bunyan to Beckett* (Baltimore and London: The Johns Hopkins University Press, 1974), p. xii.

which a performer prefigures their audience, the term implied starrer may highlight how this prefiguring may be done by the creator — at first — from a power of deference or (more likely) from a disempowered position. Garland-Thomson's claim of the stare as dialogical opens up possibilities for creators/artists to approach this relationship with on more equal footing.

By employing the term implied spectator here, I also hope to demonstrate what might be at stake when different spectators are implied by the performer, how different performers configure their concept of a piece's audienceship, and how a misreading of the spectator (either consciously or not) may have explosive results. As Iser writes, "the reader [of a given text] is forced to discover the hitherto unconscious expectations that underlie all his perceptions, and also the whole process of consistency-building as a prerequisite for understanding".⁴¹ The process by which a performer creates and puts forth unconscious expectations from an audience is essential to understanding a performer's intentions and methodology, and it is not only when considering illness/non-normative bodily experience that such an issue arises. With visibly marked non-normativity however, such as with physical disability, firm us/them dichotomies may be established — as they would do with racial or gender difference, which is a territory previously discussed in relation with Garland-Thomson's *Staring*. This issue, however, becomes increasingly complex when considering 'invisible illnesses' such as epilepsy or mental illness, which generally do not have visibly marked non-normativity. The relationship between performers with these illnesses or experiences and the expectations from their audiences/spectators may be even more complex. However, the relationship between hyper-aware performers and an audience

⁴¹ Iser, p. xiv.

which is conceived around its willingness to accept a performer's presumptions of his or herself highlights how a performance might configure a relationship with an audience as either allies or adversaries.

The first item that is key to the relationship between live performer and audience, as might be highlighted here, is that the performer will consider its audience when making the work. While this may seem obvious, some contemporary performance practice — especially solo autobiographical work — seems responsive to their implied spectators, both by the makers and the audiences, because of the works' often conversational tone, such as with Lisa Kron, or with a lack of separation between performer and audience. Kron, whose work includes *Well* (2006) and *2.5 Minute Ride* (1999) among other monologues, often interrupts her performances to 'check in' with her audience, consciously forming them into allies who share her humiliations and discomfort while recognising that the material may have (or hopefully has) personal resonance for audience members.⁴² This lack of separation, as evidenced by Kron but shared by many, may imply a dialectical relationship in which the performer has considered the expectations of the audience, but they may also be playing on these presumptions. Although this scene from *Sick* featuring Sara demonstrates the gaze and implied presence of an audience with certain expectations about propriety, the previously considered scene was not a consciously crafted performance work such as a poetry reading or framed performance, which Flanagan produced as his artistic oeuvre. By providing close readings of the work of the following two performers, Rita Marcalo and Bobby Baker, and through interviews with them, I will attempt to examine how a performer consciously considers, protects and provokes that intended, implied

⁴² Lisa Kron, *Well* (New York City: Theatre Communications Group, 2006), p. 12.

audience. Both of the following case studies also engage with my performance practice and the questions that arise from it. I hope my experience allows analysis of these interviews, which reveal critical production details about how performance work is created, marketed and ultimately translated to audiences, and how this process can be burdened by misunderstandings, embarrassment and discomfort when the material in question relates to non-normative bodily experience.

'EPILEPSY AS ART?' Rita Marcalo and 'The Community'

On 24 November 2009 the UK-based charity Epilepsy Action released the following statement on *Involuntary Dances* at the Bradford Playhouse:

We recognise that everyone is free to make choices about their own health. However, we are very concerned that a person with epilepsy would stop taking their anti-epilepsy medication voluntarily in order to induce a seizure. This is potentially very dangerous and something we would strongly urge this person not to do. Seizures can bring with them the risk of injury from jerking or falling and, in the worst cases, death.

People with epilepsy should not make any changes to their anti-epilepsy medication without consulting with their doctor first.

It is also concerning that the performance could influence others to do something similar. At the very least, the performance should carry a health warning advising people that they should not attempt this themselves under any circumstances.

We've had several complaints about this. I'm sure that many of our members would also consider the performance inappropriate.⁴³

In November 2009, Rita Marcalo's work became the subject of an extraordinary controversy in the media, which brought strongly to the forefront the relationship between institutions, advocacy organisations and independent artists. When I interviewed Marcalo on 5 April 2010, she was only just beginning to process all

⁴³ 'Statement on *Involuntary Dances*', *Epilepsy Action Network*, November 2009, <<http://www.epilepsy.org.uk/about/positionstatements/ritamarcalo>> [accessed 5 April 2010].

that had happened. Marcalo's dance trilogy *Involuntary Dances* was a personal investigation into her experience living with epilepsy. As a choreographer, her artist statement reads: "my body is about control. I have spent years training it so that I gain 'mastery' or control of it. However, there are these episodes in my life where I don't have any control over what my body does, the movements it does."⁴⁴ In *Involuntary Dances*, the first piece in the trilogy, Marcalo's exploration of bodily control resulted in the creation of a 24-hour performance in which, locked in a cage, she participated in all of the activities she normally avoids in order to prevent seizures. A month earlier, Marcalo had stopped taking her anti-convulsive medication and that evening, among other activities, she drank alcohol, ate dark chocolate, denied herself sleep and stared at flashing lights. Her participation in these activities was an attempt to induce a seizure, which would then be filmed or photographed by the audience. The journey and production of *Involuntary Dances* is documented by an online review by Jo Verrent, who intersperses the atmosphere of the intimate performance at the Bradford Playhouse with her own real-time responses to the work.⁴⁵ Because I was not at the performance event, I rely on Verrent's account (cited above) and my interview with Marcalo as the documentation that will be the subject of my analysis for exploring *Involuntary Dances*, alongside online reviews, comments to online reviews and other media. Because, reiterating my Introduction, the object of study in *Playing the Cancer Card* is performance documentation and the affect of performance, as opposed to performance itself, this chapter does not contain a full analysis of either Marcalo or Baker's performance work. Given

⁴⁴ 'Frequently Asked Questions', *Bradford Playhouse Homepage*, <<http://www.bradfordplayhouse.co.uk/rita/faq.html>> [accessed 5 May 2010].

⁴⁵ Jo Verrent, 'Review: Jo Verrent sees Rita Marcalo's *Involuntary Dances*', *Disability Arts Online*, 12 December 2009, <http://www.disabilityartsonline.org/?location_id=1110> [accessed 18 January 2010].

the amount of response to their work (international controversy and/or significant participation in extended conversations/campaigns on advocacy) the affect of performance feels as pressing and relevant an object of study as any.

First billed by Marcalo as “half pyjama party, half voyeuristic pleasure”⁴⁶, *Involuntary Dances* playfully attempted to explore her own bodily experience (to which she is not normally consciously privy) and a larger societal interest in voyeurism and how people watch other, particularly marginalised, bodies. While she thought the piece would make people uncomfortable — the space in which she usually presented work refused to show *Involuntary Dances* (the name of which she preferred not to disclose) saying the piece was a “step too far” out of her normal practice — she expected the work would receive local press and perhaps interest as far as to Leeds (20 miles away) at most. When Epilepsy Action put out the aforementioned statement on the work, the performance was, however, quickly picked up by an array of media writing both in support and as critical of the performance’s mission.⁴⁷

In finishing its position statement with “We’ve had several complaints about this. I’m sure that many of our members would also consider the performance inappropriate”, Epilepsy Action makes a claim about community, which invites further analysis here. By positioning themselves as an organisation representing a number of members (the exact number is unclear from the statement) who have complained (the number of complaints they received about the work is also unclear), Epilepsy Action makes a claim that there is a ‘community’ which Marcalo has offended. Miranda Joseph, in her

⁴⁶ Appendix A, p. 297. All quotations in this section, unless otherwise noted, are taken from the interview I conducted with Marcalo in Ilkley in April 2010, available in full in Appendix A.

⁴⁷ Marcalo’s work was discussed in major news blogs including *The Guardian*, *L.A. Times*, *Daily Express*, *The Telegraph* and on the BBC, all between 19-20 November.

introduction to *Against the Romance of Community* demonstrates that the invocation of ‘community’, although “almost always invoked as an unequivocal good, an indicator of a high quality of life, caring, selflessness, belonging” can be as destructive and divisive a force as any.⁴⁸ While I will use the term community throughout this chapter, I will do so with the unstated, but ever present suffix ‘-as-they-define-it’ in hopes of appreciating that the various parties’ invocations of community is always done as they define ‘the community’ or, rather, *their* community. Joseph, who argues for a more rigorous and critical engagement with the nebulous term ‘community’ provides numerous examples of how “communal participants are not identical, and many of those to whom an identity is attributed do not participate in communal activities”.⁴⁹ Marcalo’s performance, I argue, highlights exactly this non-participation and demonstrates a strong example of the consequences, which a non-participant might face. While I aim to offer a critique of Marcalo’s performance, which draws attention to her underestimation or non-consideration of disability discourses when marketing of work, I also plan to show how Epilepsy Action, as an established voice on issues of epilepsy and stigma, may be guilty of invoking their authority in the ‘community’ to such an extent that it trumps all other voices and directs the public conversation about epilepsy in a conservative direction.⁵⁰ By positioning their needs, as an organisation, up against the artistic goals of Marcalo, I hope to highlight the particularities of their collision and describe its

⁴⁸ Miranda Joseph, *Against the Romance of Community* (Minneapolis: University of Minnesota Press, 2002), p. vii.

⁴⁹ Joseph, p. vii.

⁵⁰ Joseph, p. xiii. Joseph provides an excellent example of this in her discussion of the Rhino Theater. As older board members and associated artists demonstrated their ‘battle scars’ and discussed their traumatic history relating to the theatre, they were able to easily trump all outsiders’ suggestions, a process which Joseph, correctly so, derides as unhelpful at best, destructive at worst.

potential inevitability and/or points where misunderstandings could have been eased.

For Marcalo, *Involuntary Dances* represented her first project about epilepsy and she describes the work very much as a ‘coming out’ not dissimilar to her process of coming out as a lesbian. While she found a sharp metaphor for herself with the cage and the voyeurism, it is clear that Epilepsy Action viewed the work as a reiteration of the historical trope that people with epilepsy are to be caged, are dangerous and appropriately treated like freaks.⁵¹ Although their position statement looks more explicitly at her performance through a ‘public safety’ angle, Marcalo’s conversations with many involved with epilepsy charities revealed that the work was being seen as a reiteration of the negative, not as a deconstruction or challenge of these tropes as had been Marcalo’s goal. An online review by Jo Verrent neatly captures the offence Marcalo’s work caused, referring to the “imagined Disability Arts Rulebook” which often polices such performances:

[The imagined Disability Arts Rulebook says] ‘Thou shalt only produce work that relates to your experiences as a disabled person according to the social model of disability’, ‘thou shalt not produce work that relates to pain or fatigue or anything that speaks of disability in a way that could be interpreted as weakness.’⁵²

From the point of view of Epilepsy Action, clearly Rita Marcalo’s performance from inside a cage is discordant with their stated goals of ‘increasing the understanding and knowledge of epilepsy by encouraging research and helping people with epilepsy achieve their full potential’, especially if they believe that

⁵¹ Marcalo presented anonymised email communication related to *Involuntary Dances* as part of the Live Art Development Agency’s *Access All Areas* symposium in March 2011. Available through the British Library.

⁵² Jo Verrent, ‘Review: Jo Verrent sees Rita Marcalo’s *Involuntary Dances*’.

her performance would encourage people with epilepsy to discontinue their medication which could lead to injury or death.⁵³

Although Rita Marcalo never styled herself as a spokesperson for epilepsy, when she was quoted as saying she hoped her performance would “raise awareness” about epilepsy, critics and those inside the epilepsy community jumped to action, as if policing how awareness will be raised. “If she wants to raise awareness”, one online posting asserted, “there are more tasteful ways of doing it”.⁵⁴ This seems reminiscent of responses to i[2]y’s cancer bracelet fundraiser, or to the work of writer/performer Tania Katan who, after two mastectomies, claimed to ‘raise awareness’ about policed bodies by running topless at breast cancer charity races. Katan was often asked by the runs’ organisers to put her shirt back on.⁵⁵

The job of raising awareness, even in the most broad, popular usage of the term, seems to fall under the explicit remit of organisations like Epilepsy Action and falls nebulously inside the remit of artists and performers creating work about a given topic. While *Involuntary Dances* is explicitly about epilepsy, it is also an exploration of many issues including the desire to look, embodiment, and the marginalisation of disabled bodies. For Epilepsy Action, it is not explicitly in their remit to care about these other issues, it is only in their remit to look after how the theme of epilepsy is handled and translated to the ‘general public’. In our interview, Marcalo discusses this impasse:

⁵³ ‘EARN: Epilepsy Action Research Network’, *Epilepsy Action Network*, <<http://www.epilepsy.org.uk/research/earn.html>> [accessed 5 May 2010].

⁵⁴ Online response to Jonathan Brown, ‘Artist to have epileptic fit live on stage,’ *The Independent*, 20 November 2009, <<http://www.independent.co.uk/arts-entertainment/art/news/artist-to-have-an-epileptic-fit-live-on-stage-1824122.html>> [accessed 5 May 2010].

⁵⁵ Robert Pela, ‘Prize Fighter’, *Generation Health*, <<http://generationhealthaz.com/cover-story/35-covers/123-tania-katan-prize-fighter.html>> [accessed 5 May 2010].

I said something about raising awareness — and that just got taken and repeated all sorts of times. When I spoke about raising awareness, I was talking about — of course it's not just about me, but [the performance] came from a personal point of view. It came from the point of view as a person with epilepsy looking at notions of voyeurism in our culture, looking at this idea that you're not allowed to see, you want to see, everybody wants to see. [The performance was] looking at control, looking at behaviours [...] and also looking at the idea that someone with epilepsy is somebody that can be intellectual, can be a performer [...] So when I was talking about awareness, I was talking about a cultural commentary point of view, as an artist that's what I do [...] but then it became this other thing.⁵⁶

From this statement, it is clear that it was the word awareness ignited tension between Epilepsy Action and Marcalo. While Epilepsy Action began their aforementioned policy statement with “We recognise that everyone is free to make choices about their own health”, it appeared to Marcalo that her invocation of ‘awareness’ precipitated the taking of sides in how a community would like awareness to be raised. The audience for the work became split in two — not between those who had epilepsy and those who did not — but between those who wanted to look at the piece as a artistic exploration and those who believed the work, foregrounding the epileptic body, was explicitly and exclusively about epilepsy in society.

The splitting of the audience in two allowed for two sets of solo performances to take place — that of Rita Marcalo and those of online commentators who posted their personal stories about epilepsy to reviews and articles about Marcalo's performance — the latter of which will be analysed here. If Marcalo was capable of telling her own story using the vocabulary of live art, these commentators were sure to make their own cases and arguments known, in a manner that was suitable for them. As if they were solo performance texts in their own right, narratives about experiences with epilepsy

⁵⁶ Appendix A, p. 296.

began to pop up all over the internet. Regardless of their tone, nearly every commentator invoked the 'I' — their claim to authenticity — as justification for their anger, or their support of the work. In response to Verrent's online review, Brian Newman writes "As a person who has had seizures since the early 80s [...] the idea of inducing an uncontrolled seizure in a steel basket scares me".⁵⁷ Others defended her work using the same claim to authenticity, as demonstrated by Peter Street who writes "Rita Marcalo should really be congratulated. She has given birth to a freedom we with epilepsy have been seeking for years."⁵⁸ In his defence of Marcalo's work, *Guardian* blogger Allan Sutherland succinctly addressed this point about 'awareness raising' by writing of Epilepsy Action's response with candour:

For disability charities, raising awareness is pretty much synonymous with raising funds. What Marcalo's piece highlights is that adults with epilepsy own their own bodies and have a right to choose what to do with them. It illustrates that we are able to speak for ourselves, and don't need charitable organisations to step in on our behalf.⁵⁹

Even here, in Sutherland's argument on the whole of the controversy, he seems to employ — as if by necessity — the 'our', identifying himself as a person with epilepsy.

Some commentators spoke from the wider epilepsy community too, often speaking on behalf of children or loved ones who had died because of epilepsy. Responding to an article in the *Daily Express*, a comment entitled "MOTHER'S OUTRAGE: EPILEPSY AS ART? I DON'T THINK SO!" demonstrates in no uncertain terms the difficulties faced by families caring for

⁵⁷ Online response to Verrent in *Disability Arts Online*.

⁵⁸ Online response to Verrent in *Disability Arts Online*.

⁵⁹ Allan Sutherland, 'Epilepsy as live art isn't controversial', *Guardian Theatre Blog*, 20 November 2009, <<http://www.guardian.co.uk/stage/theatreblog/2009/nov/20/epilepsy-live-art-rita-marcalo>> [accessed 1 December 2011].

people with epilepsy — in this case a mother taking care of her son with severe seizures.⁶⁰ The commentator writes:

I AM OUTRAGED THAT THIS WOMAN IS TRYING TO TURN EPILEPSY INTO AN ART PERFORMANCE JUST TO GET £14,000. MY SON WHO IS NOW 25 HAS BEEN SUFFERING WITH EPILEPSY FOR THE LAST 10 YEARS AND I HAVE WITNESSED 100'S OF SEIZURES ALL OF WHICH I FIND VERY DISTRESSING. IT HAS VIRTUALLY DESTROYED HIS LIFE, HE CAN ONLY WORK PART TIME IN A VERY POORLY PAID JOB AND IS CONSTANTLY TIRED AND SUFFERS MEMORY PROBLEMS BECAUSE OF THE HIGH DOSAGE OF ANTI EPILEPTIC DRUGS HE MUST TAKE EVERY SINGLE DAY OF HIS LIFE.

Commenters on the *Guardian's* blog were not any more shy about their feelings as those in the *Express*, with words like 'nonsense', 'insult' and 'too far' peppering the language throughout.⁶¹ Such personal interjection demonstrates the lengths the work's virtual opponents went to have their voices heard. In our interview, Marcalo makes the claim that many people chose not to attend the performance after reading such virulent comments.⁶²

While solo performance, as a genre, exploded in relation to feminism and movements which encouraged marginalised individuals to speak and claim territory for themselves, the reaction to Marcalo's work demonstrates a dissatisfaction with this set-up: if one voice is going to speak, it better be a voice that adequately represents the community. If an overwhelming majority of people living with epilepsy and raising funds to find cures for epilepsy trust Epilepsy Action to represent their interests, Marcalo's actions become invasive at best, destructive at worst. This again highlights Marcalo's original intention for the piece — she never meant to engage in explicit advocacy (i.e., to speak as a

⁶⁰ Online response to Paul Jeeves, 'Epilepsy: Rita Marcalo Receives Grant to Induce Fit on Stage', *Daily Express*, 20 November 2009, <<http://www.express.co.uk/posts/view/141313>> [accessed 10 January 2010]. All caps appear as originally written.

⁶¹ Online response to Sutherland in *The Guardian*.

⁶² Appendix A, p. 296.

spokesperson about epilepsy) but was rather exploring her own experience with it for the first time. The ‘first time’-ness of her exploration, and the inward-looking nature of the work (i.e., not linking to a broader community) may mirror the process of growth — in relation to comfort with disability — stated by Garland-Thomson in *Extraordinary Bodies*

Like many women before feminist consciousness-raising or some black people before the civil rights movement, I saw my difference from the valued norm as a personal situation rather than as a political or social issue”.⁶³

Faced with this, the question for organisations like Epilepsy Action then becomes: how much individual action do we encourage/allow in this community when people see themselves as exceptions to the larger political or social issues at hand? And how much does a community member allow before asking people to intervene?

In our interview, Marcalo discussed at length the reactions from people doing formalised and institutionally-based work on anti-stigma campaigns and raising moneys for epilepsy research. One trope that she heard from many institutions was the idea that she was breaking the ‘rule’ not to “expose disability in any way that is funny or outrageous because it goes back to the freak show” and that her work erased years of education and reiterated the painful history of human display popular during the Victorian ages.⁶⁴ The disciplining of Marcalo may have derived from her newness to work on disability and epilepsy or a distrust that she understood the existing histories of and discourses around freak shows. If she, as a newcomer to the material, highlighted only the voyeuristic aspects of how people with disabilities are

⁶³ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), p. ix.

⁶⁴ Appendix A, p. 295.

watched and policed, she may be leaving unconsidered a rich body of work (both scholarly and artistic), which has brought up similar issues. Garland-Thomson describes this phenomenon quite pointedly:

Those of us with disabilities are supplicants and minstrels, striving to create valued representations of ourselves in our relations with the non-disabled majority. This is precisely what many newly disabled people can neither do nor accept; it is a subtle part of adjustment and often the most difficult.⁶⁵

Although Marcalo is not newly-disabled, her work demonstrates a first attempt to incorporate epilepsy into her work, and to disclose her epilepsy in a professional context. Marcalo's creation of the work may be a subtle part of the adjustment process Garland-Thomson describes. If this is the case, however, it was clearly not subtle enough for those with epilepsy who may have already adjusted and are now accepting (if not fervently against) the politics of themselves as unwitting spectacles.

While the freak show is a trope that has been applied in work related to disability and colonial subjectivity, Marcalo's unglamorous approach to the freak-dom may have made the work too subtle to be read as a commentary on, or an attempt to problematise, such a discourse. Marcalo, locked in a large cage — reminiscent of a dog cage — performed the work in a relatively small theatre for a small audience, so the audience's activity of the gawk or stare may not have felt particularly intense or threatening. Compared to Coco Fusco and Guillermo Gómez-Peña's performance *Undiscovered Amerindians* (1992) — in which the couple displayed themselves as recently discovered peoples locked in a cage in the foyers of major natural history museums across the world — the context of Marcalo's work — as a live art event for a small audience compromised of friends and other performers — felt intimate, lessening the

⁶⁵ Garland-Thomson, *Extraordinary Bodies*, p.13.

obvious comment on the policed, Othered, subject as Fusco/Gómez-Peña's did about colonial bodies.⁶⁶ Similarly, Mat Fraser's performance *Sealboy: Freak* (2001) employed tropes from classic freak shows, which are quite literal references to a long history of displayed bodies. Aside from being based on a historical figure, Stanley Berent — who shared, with Fraser, phocomelic (very short) arms — Fraser performs 'tasks' with his short arms and boldly addresses his sexuality and sexual capabilities.⁶⁷ *Sealboy: Freak* presents the work with an entertainer's smile and a circus barker's bold tone with recognisable points of reference for audiences. Even if audiences are uncomfortable with Fraser's self-display as a freak, he makes clear the history ('Step right up, Step right up') from which the work is drawn. If Marcalo fails to frame her critique of the freak show as boldly as *Sealboy: Freak* or *Undiscovered Amerindians*, she is undoubtedly engaging with the theme of voyeurism and how it might relate to current discourses on, as Koppers describes them, "the acts of surveillance, self-discipline and focus on oneself as freak [which] characterises much of popular culture and everyday life".⁶⁸ What *Involuntary Dances* does, however, is to engage with these discourses as they relate to epilepsy, a generally invisible disability, one much less instantly readable as Fraser's physical non-normativity or Fusco's race. By displaying the epileptic body as freak, even when not in the midst of a seizure, Marcalo's performance inserts people with epilepsy (and, more specifically, herself as a woman with epilepsy) into discourses previously reserved for those with physically non-normative characteristics.

⁶⁶ Joshua Sofaer, *The Many Headed Monster* (London: Live Art Development Agency, 2009), p. 42.

⁶⁷ Petra Koppers, *Disability and Contemporary Performance: Bodies on Edge* (New York: Routledge, 2003), p. 36.

⁶⁸ Koppers, *Disability and Contemporary Performance*, p. 36.

In addition to Marcalo's play on the theme of freak, the cost of *Involuntary Dances* generated significant media interest. In a nation and national moment in which arts funding is precarious and controversial, the £14,000 project was framed by critic Paul Jeeves, writing in *The Daily Express*, and online commentators as a waste of money which *could* or *should* have gone to epilepsy research, social services for people with epilepsy or anti-stigma campaigns. As the aforementioned mother writes, "THE ARTS COUNCIL SHOULD GIVE THIS MONEY AND INDEED ANY SPARE CASH THEY HAVE TO ONE OF THE EPILEPSY CHARITIES WHO WILL PUT IT TO GOOD USE UNLIKE MISS MARCALO."⁶⁹ This critique, however, both confounds and simplifies any discussion about budgeting around medical research and/or arts funding, and provides a cover for the policing of marginalised bodies, ensuring that they remain pure, agreeable and free from politicisation. For Marcalo, the budget for the project pays artists, rental costs, marketing and materials where, for those critical of the work, the money *steals* from epilepsy research. If *Involuntary Dances* was an advocacy campaign with which people agreed, they might not have a problem with the expenditure, but Marcalo herself never made a claim that the money was related to epilepsy research nor was it funded, by Arts Council England, to serve a specific epilepsy advocacy agenda. Because some people felt the message was disagreeable, however, the money was seen through the distorted lens of how epilepsy funds were depleted in order to fund the project.

The question of editorial control being commandeered by Epilepsy Action and simultaneous critiques of the performance's expenditures came into focus in June 2010, when the organisation contributed advertisements to a for-profit

⁶⁹ Jeeves, cited above, headlines the article "Rita Marcalo Receives Grant to Induce Fit on Stage".

“advertising insert” in *The Guardian*. The insert, published by Mediaplanet, features eight articles written about the challenges faced by people with epilepsy, inspirational stories of people with epilepsy and news about current scientific research. These articles are flanked by advertisements by related organisations and businesses, from schools for students with epilepsy and special needs to carrying cases for pills. Billed as an “advertising insert”, the Mediaplanet business model is based on providing editorial content on a given subject and then matching “both the needs of [their] targeted readers/viewers, and the commercial solutions presented to them by our advertisers...”⁷⁰ This fact raises attention to how and why Epilepsy Action, having taken out what was assuredly a costly 1/3-page ad with Mediaplanet (over which they may have only limited editorial control, and certainly was not published by themselves) and in such a major national press moment, would choose to police, so aggressively, a work which could, at most, be seen by 150 people.⁷¹

The relationship between accessibility to information about epilepsy and accessibility to the art form — live art — employed by Marcalo to ‘raise awareness’ may be crystallised within the above numbers. For Epilepsy Action, Marcalo’s work, with a provocation it found distasteful, failed to draw forward-moving attention to epilepsy — as was clearly done by Mediaplanet’s overall positive framing of epilepsy and people within epilepsy communities. Further, Marcalo engaged with epilepsy through the mode of live art (citing Franko B and Orlan), the practitioners of which are often critiqued as less-accessible as opposed to, for instance, the clear and unembellished language employed by

⁷⁰ ‘About Mediaplanet International’, *Mediaplanet International* <<http://www.mediaplanet.com/about#top>> [accessed 23 January 2012]. I consulted Mediaplanet on the information above but they preferred not to have the costs of their various advertisement sizes published.

⁷¹ 150 is the capacity of the Bradford Playhouse’s space. In my Appendix A, Marcalo describes that, due the intensity of the fervour against her performance, about 40 people attended *Involuntary Dances*.

Mediaplanet's articles or Epilepsy Action's website. Internet commentary about Marcalo's work is riddled with 'so-called-artist', a term meant to belittle the arts practice and may demonstrate a discomfort with live art and the relationship between live art communities and a more general public.

A critique of Marcalo's work may be made as to why the 'awareness' that she mentions — as in an awareness to a non-specialised public about the cultural issues surrounding epilepsy — is not able to be mobilised in a manner such as with the work previously described, by Douglas Crimp. The activist aesthetic he espouses moved work about HIV/AIDS beyond expected dichotomies of work being either 'humanising' (of people with HIV/AIDS) or 'fundraising' for a cure. Had Marcalo been interested in the 'awareness' as she defined it, there may have still been a possibility to move the work beyond being a fundraiser for epilepsy research or a work which humanised people with epilepsy and she could have demonstrated how cultural stigma around epilepsy can have tangible destructive results. The claim could also be made, however, that my even suggesting a necessity to engage with epilepsy, as a subject matter and in such a way, may be an ultimately ableist comment which expects artists with disabilities to produce work in relationship to a disability arts community. In this respect it may be telling that Marcalo consistently looked to the examples of Franko B and Orlan when defending her use of the body, writing that

The way in which I have conceptualised the performance event comes in a long tradition of live art work where artists (such as Orlan, Franko B and many others) take their body as their 'canvas', as a 'site' of performance.⁷²

This is in sharp contrast to choosing, as exemplars, prominent artists who have engaged their work in a disability arts context, at least in the past, like Mat

⁷² Marcalo quoted in 'Frequently Asked Questions', cited above.

Fraser or Alison Lapper. As will be discussed later in this chapter, it may be Marcalo's own considerations of her identity as an artist with a disability which affects the models with which she chose to engage.

All commentators (both in emails, online comments and press coverage) were clearly responding to Marcalo's work in a way, which from an artistic perspective, felt relevant to Marcalo. Marcalo describes the adverse reaction to the work as hardening her resolve to create the piece and place it before an audience.⁷³ The clash of worlds — the advocacy world and the artistic world — could not have had lines more clearly drawn. To relate the conflict in terms of Iser, it was Marcalo's mis-reading of her potential audience (thinking it would only be a live art crowd and would not draw attention from the epilepsy communities), which led to her prefiguring of a single spectator who was different than the myriad of spectator experiences which were actually present (or who commented on the work without seeing it). Although the piece was not prohibitive to people with disabilities or with epilepsy specifically, the marketing of *Involuntary Dances* did not actively seek their participation as either spectators or as research/reference points. Marcalo instead seemed to have focused her work — reflections on voyeurism, control — away from a disability arts reading and towards a live art/contemporary performance milieu. While the choice of the conversation's tenor is her prerogative, the spectators — to the debates and coverage even more than just the performance — did not only include audience members familiar with live art or live art discourses. With this being the case, the pre-structuring (as Iser describes) of her performance, whose meaning is meant to be unfolded by the spectator, conflicted with the organisations and individuals who had been engaged in conversations about

⁷³ Appendix A, p. 296.

epilepsy for many years. This analysis of Marcalo's work is only possible with the performance documentation being the object of study as the performance itself did not change based on the controversy seen in the media. The controversy, however, became essential to Marcalo's reading of the piece and, undoubtedly, how the piece will be remembered.

In *Autobiography and Performance*, Deirdre Heddon writes "The assumed authenticity that attaches to experience serves to equate it with 'authority' and personal experience can easily become an unwitting but persuasive guarantor of 'truth' [...] 'I' become the evidence."⁷⁴ In relation to *Involuntary Dances*, what is present is a differential on position and from the different perspectives from which people were making experiential claims to truth. While those offended by her performance seemed to believe Marcalo was advocating, through her solo performance, that all people with epilepsy should discontinue their anti-convulsive medication, Marcalo was not using her performance to relate to an epilepsy community, either real or imagined. As Rita Marcalo readily admits,

I hadn't thought about how this work was going to fit in with [discourses about disability] or not... I wasn't there as a disabled person, this was on my way in... I suppose what I am trying to say is that I was aware of [the discourses] but I hadn't located myself in them.⁷⁵

It was this process of location that seemingly agitated those inside the epilepsy community. While questions of authenticity might appropriately relate to her as a community artist working with disability — as she had not engaged before — many online commentators wrote about whether or not Marcalo was actually epileptic, if, perhaps, her seizures had ceased, or if the entire performance was

⁷⁴ Deirdre Heddon, *Autobiography and Performance* (Basingstoke: Palgrave Macmillan, 2008), p. 26.

⁷⁵ Appendix A, p. 297..

a hoax. “Probably isn’t even still epileptic, but recovered,” one voice wrote in response to Bradford’s *Telegraph & Argus* newspaper’s post-performance coverage, “it does happen and people paid to view such a sham...”.⁷⁶

The policing of identity, and hierarchy of suffering — the claim that Marcalo does not suffer ‘like the rest of the people with epilepsy’ — was reaffirmed on online comment boards again and again. As Anna Kennedy wrote, “It seems this young woman only has two seizures a year, I have already had two seizures in the past three days”.⁷⁷ The severity and regularity of her epilepsy is something that Marcalo herself commented on, saying “Up until [the performance], I felt like I didn’t have the right to call myself to a disabled person because my epilepsy is for the most time controlled. It didn’t feel like my identity”.⁷⁸ When considering definitions of community, Garland-Thomson writes about how ‘little somatic commonality’ exists between people with different disabilities: “Only the shared experience of stigmatisation creates commonality”.⁷⁹ Although Marcalo and the commentators are all people living with epilepsy, the myriad of different kinds of seizures and levels of severity/regularity essentially make Marcalo and many commentator’s experiences of epilepsy completely different, thus raising the question of usefulness and the efficacy of Marcalo aligning with a community with which she has very little in common.

⁷⁶ Online response to Tanya O’Rourke, ‘Controversial epileptic ‘fit’ performance ends in failure’, *Bradford Telegraph and Argus*, 12 December 2009, <http://www.thetelegraphandargus.co.uk/news/local/localbrad/4790933.Dancer_Rita_takes_a_step_into_the_unknown/> [accessed 18 January 2010].

⁷⁷ Online response to Verrant.

⁷⁸ Appendix A, p. 294.

⁷⁹ Garland-Thomson, *Extraordinary Bodies*, p. 15.

The policing and questioning of ‘who’s in and who’s out’ is perhaps a symptom of invisible disabilities like epilepsy or mental illness, and it remains difficult territory, especially considering how Marcalo ‘passed’ as non-disabled and/or well for many years as a conscious professional choice. Because self-definitions and disclosure of disability status, in the United Kingdom, can relate directly to access to resources (i.e., receiving free prescriptions or not, amongst others) and privileges/oppressions and inclusion/exclusion from epilepsy and more general populations, this inter-community(ies) conversation seems unsurprisingly policed with a suspicious, or at least not always generous, tone, as shown above. *Involuntary Dances*, however, was a useful moment which incited a community into critical self-reflection and effectively brings to the foreground how the authority of the solo performer, or of the evidentiary ‘I’, can clash when members of the seemingly-similar populations are protecting their individual interests — be they artists, advocates, fundraisers, or people with a unique bodily experience and a story to tell.

Bobby Baker and the Minefield of Language

Online biography for Bobby Baker posted on the Wellcome Collection’s website:

Bobby Baker is a woman and an artist. She is commonly described as a performance artist or live artist, and is one of the most widely acclaimed and popular performance artists working today. It is true that she does perform and is alive but she also works in other media, including radio, TV, film, painting and drawing. Over the past 11 years she has periodically gone mad and is an active campaigner for more acceptance of and human rights for people categorised by society as ‘disordered’.⁸⁰

⁸⁰ Online biog for Bobby Baker in ‘Bobby Baker in Conversation’, *Wellcome Collection*, <<http://www.wellcomecollection.org/whats-on/events/bobby-baker-in-conversation.aspx>> [accessed 6 May 2010].

Bobby Baker is comfortable talking about mental illness, but she has not always been. If *Involuntary Dances* marked Rita Marcalo's 'coming out' about epilepsy in 2010, Baker's 'coming out' happened in 2000 with *Pull Yourself Together*, her performance intervention promoting Mental Health Awareness Week which I have previously discussed in Chapter 1. In her ten years of creating work about mental illness, Baker's explorations have been both public and private, resulting in her most public work to date, *How to Live* for Barbican BITE in 2004, and her most private, 11 years worth of diary drawings which only became public in 2009. In both of these cases, Baker has consciously considered her audience — including both people experiencing mental illnesses and people who have not/are not — in the work-creation process, but not always in the same way. In Chapter 1, I provided a reading of Baker's *Diary Drawings* exhibition at the Wellcome Collection, trying to locate how her professional silence around mental illness may be included inside a theoretical discussion of her work. In this chapter, I base my examination on my interview with Baker in which we discussed how she has negotiated her activism and advocacy around mental illness through professional strategies, such as marketing. By examining her strategies, I will contrast her approach with that of Marcalo, and identify where approaches to an 'implied spectator' or multiple implied spectators, may have drastically different outcomes.

During the interview I conducted with Baker in April 2010, she framed her conception of audiences (both performance audiences and the audiences consisting of people around her like family and friends) in the language of 'theory of mind'. Theory of mind is the psychological 'jargon' — as Baker describes it — of how people implicitly respond to their projections of the opinions and judgements of others. About 'theory of mind', Baker commented:

Putting yourself in other people's shoes. I've always had a rather generous proportion of that. So if things become distressing I spend my whole time worrying about everyone else, forgetting who I am. So it's always been natural to me to think about what others are going to get out of what I'm doing [...] Sometimes it's gone a bit too far.⁸¹

Such a consideration of the audience has always been a characteristic of Baker's work, but when creating *How to Live*, she felt more conscious of this position than before. Her perspective, however, was not from the point of view of a mental health advocate, but rather as a woman uncomfortable disclosing her mental health status and trying desperately to negotiate multiple audiences at all times. It was perhaps because of her non-disclosure that her approach to her implied spectators was as multivalenced as it was. First there was her family, who she knew would see the work, and who came to the work with an intimate understanding of the context. Secondly, there were the doctors whom she was collaborating with on a performance piece about mental health and Dialectical Behavioural Therapy (DBT), some of whom knew about her treatment course and first hand experience, while others did not. Thirdly, there was the audience of producers, technicians, directors and marketing staff at the Barbican, few of whom Baker informed about her mental illness for fear of being treated awkwardly. Finally, there was the *audience* audience, the 1,000 people each night at the Barbican Theatre who were coming to see her largest performance to date.

Created for BITE (Barbican International Theatre Events) at the Barbican Theatre in London in 2004, *How to Live* was developed in consultation with Richard Hallam, a clinical psychologist, and followed Baker as she described her personal re-imagining of DBT. Baker, instead of using herself as a patient,

⁸¹ Appendix B, p. 301. Interview with Bobby Baker, 15 February 2010. Interview available in full in Appendix B.

positions herself as psychologist in the performance and enacts her therapy on a pea, enacted by a pea on a string. The pea occasionally interjects its own thoughts or protestations (during which time Baker sits silently and nods along with the silence as if in agreement). The stage picture is that of a dominating medical institution towering over a (mostly) helpless pea. The performance contained many signature elements for Baker, and in particular included the performance being built around short vignettes, each with their own signifier, ultimately building to a fantastical conclusion. In this case, each of the vignettes, or chapters, was one of 11 strategies of *How to Live*, each with a distinct title — when put together, the titles formed an acronym, revealing the ultimate strategy of Baker’s therapy course: W.A.T.C.H. Y.O.U.R.S.E.L.F.

What distinguishes *How to Live* from Baker’s previous work, however, is that it lacks the personal and straightforward autobiographical anecdotes, which characterised *Box Story* (2001) or *Drawing on a Mother’s Experience* (1988). Aside from two chapters which featured reflections on “Person A” — a clear reference to Andrew Whittuck — the relationship between the text and Baker’s personal life remain obscured and ambiguous. In John Daniel’s *On Tour* piece about the production, Baker’s relationship to DBT is both subtle and incredibly under-exaggerated. While Daniel writes that “Baker’s taking the bravest step of her career by going public with her own experience of the mental health system”, the article never pins her down as *the* person who is experiencing the therapy that is being explored.⁸² Instead, he describes the show as “Inspired by her own experience of being treated with Dialectical Behavioural Therapy (DBT) — a form of Cognitive Behavioural Therapy developed to treat people with mental health issues ranging from phobias to more critical personality

⁸² John Daniel in Michèle Barrett and Bobby Baker, *Bobby Baker: Redeeming Features of Daily Life* (London and New York: Routledge, 2007), p. 248.

disorders”, thus allowing Baker to pass as a patient anywhere on this spectrum.⁸³ My discussion of this subtly is not intended as a swipe against her nondisclosure but rather to highlight the steps taken by Baker to reveal her relationship with mental illness in a measured manner. Because Daniel’s description provides both a range of experience for people’s engagement with DBT and avoids identifying the severity of Baker’s personal experience, the written accompaniment to *How to Live* continues Baker’s pattern of non-disclosure, at least about the specific severity of her experience.

It is in retrospect that Baker discusses how she had not fully disclosed living with mental illness when creating *How to Live*, but even at the time of production, there were a few hints that the audience was privy to something deeply personal yet obfuscated. In the middle of the performance, Baker looks directly at the audience and asks, “People would never admit to the public that they had disorders, would they?”⁸⁴ This pointed moment (although perhaps more gentle when people do not know Baker’s personal history in relation to the text) clearly demonstrates that Baker was edging towards a ‘coming out’, or, if not a coming out, a challenge to her audience about what might be gained from such a disclosure or how the mental health of the performer matters to the piece’s reception.

Baker readily admits that the show was dangerous to her mental health — the pressures of performance were great and the conversations around the work were challenging. While the work was not autobiographical, it wasn’t *not* about her either. Although the marketing material attributed the inspiration of the work to Baker’s own experience with DBT, the piece demonstrated a silence

⁸³ Daniel in Barrett and Baker, p. 246.

⁸⁴ *How to Live*, Bobby Baker (Daily Life Limited, 2007).

around the severity of her mental illness and an ambivalence about her personal relationship to the treatment course and those who practice DBT. The stigma around mental illness, which Baker so consciously works to lessen, presumably kept her from being open about her treatment course at that time. It was this uncertainty, Baker says, which led ultimately to the tone of the work being as cheering and optimistic as it was:

The whole process was very risky for my health, but I was sort of on this mission. But at the same time, with this kind of determination and some kind of necessity to do it, this extraordinary energy... Funny enough that what happened was this kind of phenomenally cheering show where, in many parts, I did protect those people who saw the show from how ill I was[...] There was this unconscious need for them to see how I learned to cope with those 11 skills, to get a sense of poignancy with the patient and the image of the pea, and actually probably not been able to — because of where I was personally — but also with an intuitive sense of wanting to protect people, to say that this pea was me.⁸⁵

With this quote, it is evident that non-disclosure does not, as Frank discussed in *The Wounded Storyteller*, equate to non-understanding, or to harmful outcomes. While the ‘cheering’ show was, indeed, incredibly difficult for her to produce, Baker’s description of the process demonstrates that the by-product of non-disclosure can appear incredibly different than what might be expected, especially tonally. On the other hand, it may be exactly because of her non-disclosure that such a cheering show *had* to be made, lest Baker appear too ambivalent about her health, or appear to be a person undergoing intense DBT. Unlike Marcalo, Baker made very few strong statements and presented few controversial images surrounding DBT and mental illness more generally. This potentially shielded her from controversy when dealing with mental illness. As she was exploring her place in discourses about mental illness, she used a light

⁸⁵ Appendix B, p. 300.

touch and an ambivalent position to explore how society views issues around mental health.

After *How to Live*, when Baker became active in mental health advocacy — as a personal conscience-raising occurred around her stake in mental health debates — Baker described how her role, or the sense of her role, shifted. “I found myself really caught up in being a spokesperson and I got so politicised. I was a fountain of facts, all I could do was quote statistics...It was exhausting and overwhelming and I was really learning a lot”.⁸⁶ The sentiment she discusses here demonstrates how Baker conceived of the process of being a spokesperson and activist precluding her from being an artist at the same moment. It was as if serious, considered live art and explicit advocacy or spokeswomanhood needed to be completely separated, at least by Baker, and her identity became exclusively that of a spokeswoman for mental health. Baker’s shift away from performing, however, was brief, and she soon discovered her role in the mental health community/communities might be more complex. About her identity as a spokeswoman she said “I finally got [to realise] ‘Hey, I’m an artist. I’m an artist, actually.’ There are people who do [service user representing] really well... I’m this, and if things work, I’m funny. That’s all I can do. That’s my contribution”.⁸⁷ Baker’s discussion of finding her place inside of advocacy vividly demonstrates the process that Marcalo touched upon but was unable to do convincingly (at least to Epilepsy Action) because Marcalo’s contribution was announced retroactively. For Baker, finding her place inside advocacy before becoming an outspoken voice in performance allowed her to, preemptively, enter her conversations around mental illness (such as that with

⁸⁶ Appendix B, p. 306.

⁸⁷ Appendix B, p. 306.

the Wellcome Collection) with seeming-confidence and authority, demonstrating, as Crimp might describe, an ‘altered’ artistic practice which incorporates activism at its core.

Baker’s relationship between her activist self and her artist self came together with her 2009 exhibition *Diary Drawings* at the Wellcome Collection. While the decision-making process before exhibiting all of her drawings from her private collection was not easy — describing her role and the work as somewhat ‘sacrificial’ in nature — Baker’s history with mental illness had, by 2009, been long public and had included *How to Live* which had been supported with funds from the Wellcome Trust. Her involvement with the community (as she defined it, to her) made her responsiveness and interaction with her audience even more loaded — she now knew the needs of the community, the tenor of the public discourse, and the ‘stares’ that advocacy on mental illness looked to address. In practical terms, Baker was able to play very much to the expectation and needs of the audiences: she created a box for private comments to be shared with Baker, chose a large selection of books about mental health, and featured a list of resources for people who are mental health service users. With such a public dissemination of the work, her conception of the exhibition’s implied spectator was even more loaded, with Baker feeling an increased responsibility for those audiences who accessed the drawings and were also mental health service users.⁸⁸

For the framing of the work, Baker attempted to control as much of the marketing and public framing of the work as possible. It was here that the most interesting conflicts arose which may be the most telling of a relationship between an artist and an institution. Because Baker had been previously funded

⁸⁸ Appendix B, p. 308.

by the Wellcome Trust to create a work on mental illness that was widely seen, there was little fear that her work, or the opinions that she personally presented would be critiqued as illegitimate. In addition, the 'I' that she used in this case for evidence was clear from the large amounts of drawings (158 of 700 created were displayed) and from the texts that would accompany the drawings as captions. While people questioned Marcalo's epilepsy (or its severity), the diarising of Baker's experience demonstrates to gallery visitors that the 'I' is for real. But Baker was hyper-aware that this was not a performance in which, outside the captions, she had an opportunity to speak directly to an audience, or at least not to all of them. The gallery exhibit was paired with another exhibit, *Madness and Modernity*, which featured a very different take on mental health (focusing on institutional attitudes towards mental illness in the early modernist period, in Vienna in particular) and the Wellcome Trust's large scale marketing efforts (advertisement in Underground Tube stations, large banners outside the Wellcome Collection in Central London) ensured that many Londoners and tourists, even if they didn't see the exhibition, would be confronted with the mental health issues present in *Diary Drawings*.

In contrast to the case of Rita Marcalo, where it was Epilepsy Action policing the tenor of the conversation about illness, it was Bobby Baker who was the policing force in the development of *Diary Drawings*. Although Baker is purposefully precocious and politically incorrect in her language — for instance, her use of the term 'gone mad' in the biographical note at the beginning of this section — she was exacting in the language that she felt was appropriate for all press materials associated with the exhibition:

[The assistant in marketing] had used all the words you couldn't use. You know, if it's your story you can say Bonkers or 'I'm a Nutter'. And it was an interesting education process for all of us, because I had to make it clear if it's in inverted commas then you

can use that language. But I also know the political, psychiatric world. The language was the hardest thing I was ever involved in with there. All of us kept an eye on those words. Do you say Mental Health problem? Mental health difficulty? It's such a minefield, and I have strong feelings about it.⁸⁹

Thankfully for Baker, the marketing staff at Wellcome seemed responsive to her leadership on such issues. Additionally — and what separates Baker from Marcalo in this case — the Wellcome Trust and Wellcome Collection's remit do not specifically deal with mental illness, but rather with medical and public education more generally. Because the Wellcome Trust lacks the rigid remit (in their Collections programme, as separate to their Arts Award funding which will be discussed in Chapter 4) or constituency of Epilepsy Action, they can allow for more diversity as to what an 'appropriate' discussion of mental illness really means. And most empowering, as happened in Baker's case, the Collection can refer to the individual creator herself to see what makes her comfortable with regard to tenor.

Entrusting the tone of the work to Baker came with an unforeseen difficulty, however, in that Baker was constantly associated with her mental illness that was at the core of the exhibition. Although Baker acknowledges a continued awareness of her mental illness, the severity of mental illness is now passed.⁹⁰ This fact, however, did not prevent people in the production team from treating Baker gently.

It was embarrassment. I couldn't understand what was going on in that whole weird phase. We couldn't get what was going on and we're pretty clued up about marketing. We couldn't get a handle on what was going on and people were tiptoeing around... There were a lot of rows going on within there... When I did a de-brief with Rosie afterwards, I told her that it would have been so much

⁸⁹ Appendix B, p. 303.

⁹⁰ In her new publication, Baker describes herself as "sane as a sandwich board". Bobby Baker, *Diary Drawings: Mental Illness and Me* (London: Profile Books, 2010), p. 208.

easier to come in and sit down and be told the truth because I could have sorted it... I would put your mind at rest.⁹¹

According to Baker, it was precisely because of her history with mental illness that the marketing team was treating her with the soft touch befitting someone with current and severe mental illness. As Jim Ferris writes about disability performance in *Bodies in Commotion*, the “tendency on the part of the audience [in this case the audience of the marketing team] to assume that the performers [are] narrating personal narratives seems inevitable”, a reality which may even hold true for former illness, or illnesses that are captured in previous artistic work.⁹² While the marketers were sensitive about Baker’s capacity to handle internal conflict or deadlines, they seemed (frustratingly to Baker) insensitive to the fact that she might not want the material to tour instantly or have massive marketing efforts. As Baker described in our interview, she depended on daughter Dora Whittuck (a clinical psychologist who assisted with the exhibition’s curation), to protect these interests in meetings. It is perhaps the continued stigma around mental illness which prevented earnest and open conversations between Baker and the marketing department.

The marketing department may have fallen into a mode of thinking which foregrounded an awareness of her particular position as someone with a history of mental illness and continued to view her exclusively through that lens. Such an occasion is not unprecedented, as noted by Koppers who, discussing Arlene Croce’s 1994 non-review of Bill T. Jones’ *Still/Here* makes the critical point that by refusing the review work by terminally ill dancers, Croce “homes in on an underlying cultural assumption: people who are defined by their bodies are

⁹¹ Appendix B, p. 303.

⁹² Jim Ferris, ‘Aesthetic Distance & the Fiction of Disability’ in *Bodies in Commotion*, Carrie Sandahl and Philip Auslander, eds. (Ann Arbor: University of Michigan Press, 2005), p. 59.

trapped by them”.⁹³ This tension was not only present in Baker’s mind, but may be a policing force in the world more generally. The back cover of Baker’s new book, the collection of her *Diary Drawings*, reads:

Bobby Baker is, in her own words, a ‘woman and an artist’. But for eleven years, while creating internationally acclaimed performance pieces such as *Box Story* and *How to Live*, she also privately battled severe mental illness. These drawings tell the story.⁹⁴

It is in here that the *but* reads so strongly, as if one cannot be an artist, a woman and a person battling severe mental illness, or at least not at the same time. While this may be an example of the necessary negotiations between personal and professional self-definitions, it may also demonstrate that people may be most comfortable with, as a narrative, people being clearly in the camp of one or the other.

Baker’s faith in the Wellcome Trust to listen to her ideas was of critical importance when considering her role as an artist and as an advocate for mental health awareness. For Baker, her former role as a service user representative — which she described previously — helped shape her relationship to mental health advocacy and has allowed her to prioritise and compromise what might be ‘artistry’ in exchange for programs which she deemed effective advocates for increased awareness of mental illness and anti-stigma campaigning. Differently from Marcalo, Baker *does* define her work and her talks as advocating for mental health awareness. In the final pages of the publication for *Diary Drawings*, Baker ensures that her politics around mental illness are not ambiguous, writing “[m]ental illness and its treatment is a subject that provokes strong feelings and, like others, I have strong opinions about what

⁹³ Koppers, *Disability and Contemporary Performance*, p. 53.

⁹⁴ Baker, *Diary Drawings*, back cover.

could help. There isn't room to fit them all in here..." and then she proceeds to make six lengthy prescriptions for the improvement in mental health services.⁹⁵

In a challenge to her roles as both advocate and artist, Baker was at first displeased when, before giving a large, public lecture at Newcastle University, the event's organisers had changed her usual biog (at the top of this section) to the following:

Bobby Baker, a well-known performance artist, has a gift for touching humorously on the absurdities and tedium of daily life. This lecture addresses the long period of intermittent depression that led to her *Diary Drawings* exhibition at the Wellcome Collection, London.⁹⁶

By removing "gone mad" from the text, Baker's initial hesitation was that the biog read as too dry, or not as an artistic statement on its own, chock full with a strong politics around language and a clear standpoint on her position in this conversation. Very quickly, however, this displeasure gave way to a mindset which saw Baker choosing to be an advocate over, at this specific moment, being an artist with complete editorial control. About Newcastle, she said:

I laughed and I made a joke about it... It was fine, and it turned out to be a very public lecture. I think I probably talked about it... It would have worked... but I think what they said was that it was World Mental Health Day and they didn't want to offend anyone. They wouldn't have done... but they didn't know what they were getting. And I was quite accepting. I was sort of annoyed and then I thought "hang on a minute — people still are very embarrassed about this — and it's a shocking subject and have a bit of humility, or patience..." Have a bit of patience about all of this...⁹⁷

While Baker clearly believes in an open tenor about mental illness — herself often using politically incorrect language — she also firmly believes that, for the goals of the advocacy campaigns in which she wholeheartedly agrees, certain

⁹⁵ Baker, *Diary Drawings*, p. 212.

⁹⁶ 'Bobby Baker: Artist', *Newcastle University*, <<http://www.ncl.ac.uk/events/public-lectures/item.php?bobby-baker-artist>> [accessed 5 May 2010].

⁹⁷ Appendix B, p. 305..

things are negotiable. This is not to say that Baker would always allow her biog to be changed, or that she would allow it to be changed in any way, shape or form although it was in this case. Rather, it was that, in this moment, artistic control gave way to patience, reaffirming Baker's alignment with Crimp and the artists involved in *Let the Record Show...* She understood the nature and size of the Newcastle audience and the comfort of its producers, and saw the talk as an opportunity to increase anti-stigma work and to insert herself into that dialogue. It was not that Baker was no longer an artist, it was just that her relationship to mental illness, and mental health advocacy did not leave her relationship to the art world unaltered. As the label in the back bottom right hand corner of her new publication summarises such a relationship, in the area reserved for ISBN codes and subject summary: "Arts/Psychiatry". Viewing the stroke in "Arts/Psychiatry" in a manner similar to how it is used in Shildrick's disabled as previously mentioned, the reconfiguration may connote that the categories are not mutually exclusive, but expresses instead a "refusal to fall in with the normative pattern of binary structure", demonstrating the various ways in which the art, psychiatry and advocacy might be interconnected.⁹⁸

Embracing the Nebulous

As much as this chapter has attempted to nail down what is at stake when artists interact with institutions, I find that the nebulous nature of both the terminology (awareness, community, advocacy) and the approaches themselves stubbornly problematic. This ambiguity, however, might be both the work's, and the theory about the work's, strongest asset. Didacticism in

⁹⁸ Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (Basingstoke: Palgrave Macmillan, 2009), p. 174

performance work seems particularly outmoded in a cultural moment in which protests are organised but remain uncovered by media outlets, and people walk down the street and ignore impassioned signs against the Occupation of Palestine the same way they ignore people handing out deals for phone cards. This is not to say that work with a stated and explicit agenda is not useful — it can be, as performance activists like Reverend Billy or protest performer Vacuum Cleaner can attest to. But there seems to be something about ‘awareness’ — its porous nature, its indeterminateness — which seems perfectly suited to performance, an exploration of bodies in space in front of an audience. Just as anti-stigma campaigns attempt to shift the slow-moving ship of public opinion about a myriad of issues, the performance work which reflects upon certain lived experience — in hopes of, as Rita Marcalo says, raising awareness from a cultural commentary perspective — demonstrates an openness for both the performer and the audience. In the case of Marcalo, I distinctly mean to include the work’s virtual audience, who accessed the work through reviews and online postings.

Although performers might be very responsive to the needs and goals of a community, as Bobby Baker and Bob Flanagan clearly demonstrate, the work continues to allow for multiple interpretations and considerations by an audience consisting of the ‘general public’. By watching the relationships between artists and the institutions working around issues those artists are reflecting upon, it may be possible to see where lines are drawn or hinted at — as with the case of Flanagan and his perception of the Make-A-Wish Foundation. This clarity doesn’t end stigma around epilepsy, mental illness, cystic fibrosis, or non-normative bodily experience more broadly, but it can help all the communities involved to self-reflect and to strategise around how they

are responding to their starers who are both inside of and outside the 'community'. It is undeniable that Rita Marcalo raised awareness of epilepsy, or that Bobby Baker raised awareness about mental illness with their respective works. What this awareness *does*, however, remains a mystery. I do not wish to imbue this mystery with a sort of power which privileges performers above other forms of activism or advocacy. Rather, I hope that through exploring Flanagan, Marcalo and Baker's work in relation to their own stated goals around advocacy, I have identified some of the strategies, negotiations and dilemmas unique to this brand of advocacy and, when not explicitly participating as advocates, this brand of performance.

Chapter 3

Music is Disease: Cancer Blogs and Spectatorial Expectation

A [Facebook] friend posted a link on my Facebook Wall to an online *Guardian* article profiling three young adults with cancer whose blogs have received national attention. While academic and media interest in blogs and youth culture are not new, the article contended that these three blogs demonstrate a movement of blog culture into exploring “more serious issues”, namely that of cancer and the isolating experience of being a young adult with a serious illness. Having seen one-too-many postings about cancer and online petitions about Health Care Reform in America, I may have read much further until I saw my [Facebook] friend’s recommendation attached to the link: “Paul’s great. You’d love this”. And I do.

The Guardian leads off with the easier two of the three profiled bloggers: two young (18 and 23 years old), very healthy-looking women whose blogs are positive, enthusiastic and have been converted into fund- and awareness-raising sites for breast and liver cancer.¹ In their pictures, they are smiling and attractive, easily identifiable as innocents, a title often attributed to those who define or are defined as cancer ‘sufferer’s. One can imagine readers responding to their images, ‘Oh, cancer is so tragic when it hits someone so young, and beautiful, with their whole life in front of them...’ When I saw the final profile, of Paul, age 27, I instantly began to devour everything about him. The first aspect that struck me was the picture: Paul looked sick. Paul did not look rosy-cancer-gentle, nor sad and forlorn, but looked ‘sick’ using the word’s multiple meanings as had been similarly implied with the title of Bob Flanagan’s documentary: sick

¹ Carlene Thomas-Bailey, ‘Young patients turn to blogs to make cancer public’, *The Guardian*, 5 July, 2010, <<http://www.guardian.co.uk/lifeandstyle/2010/jul/05/young-patients-blogs-cancer>> [accessed 10 November 2010].

as in fucked up, heavily tattooed, pierced, potentially perverse; sick as in emaciated, severely dark eyes, thinning hair from treatment; and sick, as in awesome. He was everything I ever wanted a picture of a profiled cancer blogger to be and had never seen before.

One notable aspect of Paul's blog, which separated him from the other two, was his diagnosis: Paul knew very quickly into his treatment that he was, more than likely, not going to 'survive' this cancer. While the blog very rarely talked about mortality, there was little to no survivorship jargon used. Upon hearing his complete diagnosis with bowel cancer, he wrote: "I now know what I am battling and it's going to be a hell of a fight. But I will fight it[,] that's all I can do".² The 'fight' he describes is not one of personal choice or courage — as many other cancer narratives demonstrate — but appears rather as an obligation, as if he has no other choice. As I will demonstrate further in this chapter, cancer narratives like that of Lance Armstrong are framed around the cancer patient making a conscious choice *not* to be passive and to demonstrate their heroics by taking aggressive action in the realms of fund- or awareness-raising. Paul's blog frames his conscious choice however in an anti-heroic style, as if the cancer and the situation required him to write the blog, as opposed to the origin deriving from an exceptional personal strength. It is perhaps because of this lack of choice that Paul's blog, entitled *Music is Disease*, also lacks the personal fund- and awareness-raising initiatives enacted by the other two bloggers. In this chapter, I will critically examine these three cancer blogs and consider how the format of the cancer blog may challenge conventional cancer narratives and open the pathway for a less-predetermined mode of spectatorship.

² Paul Nicholls, *Music is Disease*, 16 February 2010, <<http://www.musicisdisease.blogspot.com>> [accessed 11 November 2010].

Perhaps bowel cancer lacks the same outrageous potential (or opportunity for humorous related marketing campaigns) of, say, my testicular cancer or the breast cancer of Kris Hallenga (one of the other profiled bloggers whose awareness-raising campaign is called CoppaFeel), or that probably-going-to-pull-through-it cancers are more easily motivating than probably-going-to-die cancers. If, as Nicholl's writes, the fight is viewed as an obligation or an involuntary battle, I also can't help thinking that a serious, terminal diagnosis makes an individual less inclined to start 'a movement'. Starting a blog in such cases feels much more appropriate than pursuing fund raising strategies and marketing campaigns, especially if the founder knows that they may not live long enough to put plans into action. For Kris Hallenga and the other featured blogger, Rosie Kilburn, seemingly-non-terminal diagnoses inspired them to reach out and help others with their efforts, and the positive diagnosis evidenced that they would, more than likely, be around to see any efforts come to fruition. Although Paul's blog did not explicitly raise money for a specific cancer charity as Kilburn and Hallenga's did, he describes the blog, at its beginning, as "A release of my soul".³ Whether this release was a therapeutic purging of angst about illness, or a way to organise thoughts about impending mortality, or even a method to alert friends to future funeral plans, I found myself wanting it to be a catharsis which serves him as much as his readers.

I discovered Paul's blog in early July and Paul died on 31 August 2010, seven months after his diagnosis. In a post authored under the name Paul Nicholls, someone had written a short statement preceding funeral information:

Paul Signing Off: Paul passed away on Sunday evening in the most courageous beautiful way. He's now resting with the angels and will suffer no more. It makes his family so proud to know the

³ Paul Nicholls. 9 February 2010.

impact this blog has had on others and gave Paul great solace throughout his illness.⁴

I knew something was wrong after 3 August, when his blog went silent. There had been no updates, and continuously featured his post about his trip to London. Every time I read that post, I thought about the major effort the trip must have been from Glasgow to London. I could not help but consider the possibility of catching infection on such a journey and all the other protective cancer advice that has stayed with me since my stem cell transplant in 2002. Even more so, however, I kept thinking about how no news was not good news for a blogger with a terminal illness. Paul's blog is filled with ups and downs, with his apologies when he would write a short blog post if, for instance, he was not feeling well. But silence was never an option for Paul as he had updated his blog almost daily. I began to understand that perhaps the health risks associated with a trip to London were taken in order for him to say farewell.

In what was perhaps my own effort to know whether he was alive or dead, I sent Paul an email via Facebook, telling him how I admired the blog and wished him only health and happiness. What vacuous, selfish words they all now seem. Because we had a few [Facebook] friends in common, I felt that the short email wouldn't be wholly inappropriate at the time, but upon reflection, I know I just wanted to know whether he was alive or dead. Although I knew I was not entitled to special access to his private life, I had (along with 30,000 other viewers, according to his obituary) believed I had special access to his private life as I watched his life with illness unfold in real time.⁵ I wanted to be see how people memorialised him as all of my friends had done with Grant after

⁴ Paul Nicholls, 30 August 2010.

⁵ Catriona Stewart, 'Remember me and have a good time', *Evening Times*, 1 September 2010, <<http://www.eveningtimes.co.uk/news/editor-s-picks/remember-me-and-have-a-good-time-1.1052151>> [accessed 26 December 2011].

his death. Because of my experience with Grant, and knowing that Paul had over 1,000 Facebook friends, I knew that the online memorials (e.g. posts to his Facebook Wall or comments to his blog posts) would be an important part of the grieving and remembering process for family and friends.

I would have loved to have known if the Paul from *Music is Disease* was different than ‘real life’ Paul, as if this is a distinction that, considering the ubiquity of online social networking, even existed in 2010. I would have loved to know who took over the passwords to his blog, who posted that final blog entry, and whether we might ever see any new posts ever again. I wondered if it was a serious moment — handing over the passwords to his blog — or if it was barely a passing thought. As much as I cannot directly know the answer to these questions about Paul’s life, Paul could not have ever known how much I and thousands more isolated readers, as spectators to his life as written in *Music is Disease*, would invest in knowing him, cheering for him and mourning him.

This chapter will consider the relationship between cancer narratives and spectatorship, looking at both established cancer narratives and the way they frame audience experience, as well as cancer blogs, like *Music is Disease*, which present a person’s cancer narrative ‘in real time’. By considering narrative theory and examples of films, books and performances about illness, I will argue that cancer blogs highlight the spectatorial and interactive experience of illness for both the patient and those around them and concretise ideas of empathy and action which may have been only alluded to in previous cancer narratives as told in other modes or forms.

I will first consider conventional cancer narratives and discuss how most fit comfortably into the categories of survivorship story or bereavement story.

Although there are exceptions to these dominant categories, and narratives which blur the boundaries, I shall look at these most well-known examples to highlight — from an audience’s perspective — what is traditionally expected from a story in either realm. I shall highlight a handful of, what I see, as the most important aspects of a given story, discussing how many cancer narratives share a similar structure including diagnosis, wordlessness, the patient’s fight and stats, and either a triumphant or tragic ending. By considering my own narrative creations over the 10 years since having cancer, I will evidence some of the desires inherent in creating work around illness and provide some rationale for why, from the other end, audiences might be interested in engaging with these narratives which tell stories outside their own embodied knowledge. By setting out socially-constructed forms for telling cancer stories, I will demonstrate how cancer blogs present an intervention into the traditional forms of cancer narration, which clearly addresses both the desire for a patient to have their story told and the space for audiences to respond in kind, either with their own stories or proof that they had simply been witnessed. The audiences can respond either with a specific action recommended by the patient/blogger, or with their virtual presence being recorded by a Page View count, demonstrating exactly how many witnesses are present to the patient’s narrative.

Not Your Mother’s Illness Drama: Cancer Movies and Experimental Performance

Far from the world of yellow bracelets and pink ribbons, *BALL* is the story of a young man and his quirky and unique struggle against cancer and, more importantly, the Lance Armstrong-dominated cancer narrative. This is not your mother's illness drama - *BALL* sees all of the disgusting parts of cancer not as things which should be changed into things beautiful or inspirational. Instead, the sperm bank, the catheters, and the hair

loss take centre stage in all their glory, in a manner which is irreverent, honest, and, ultimately healing.

For six years, while touring *BALL* to medical schools and universities in the US and Canada, I used the above paragraph as the show's description in promotional materials. I have no idea what dramas I was referring to with "This is not your mother's illness drama" and yet, I understood exactly what I meant. I couldn't name one cancer story aside from Lance Armstrong's Tour de France wins, but in my head, I knew exactly what a cancer narrative was meant to be and meant to include — its plot points, its emotional trajectory and its ending which included some combination of diagnosis, chemotherapy, hairloss, sadness, and survivorship or death. I knew what was meant by Cancer or Illness Story and knew that I didn't want to be a part of that schmaltzy, sentimental body of work, and yet I had not seen or read one other piece of work around illness. The ubiquity of the overly-sentimental cancer story seemed as ingrained and oppressive as the policing of gender norms and class behaviour and yet, if pressed, I knew I could not provide one example of the kind of narrative from which I was distancing myself. My ignorance about challenging cancer narratives, although useful in many ways to my performance, did not go wholly unnoticed or unremarked upon, particularly by Linda Park-Fuller, a performance scholar and creator of her own work around cancer. Park-Fuller, in a critique of *BALL* writes:

...while I know that his aesthetic requires dismissal of traditional outcomes such as character growth and wisdom, some cancer stories provide other useful values such as political activism, psychological redress for trauma through personal validation, and rare, profound, and even ironic insights into the human experience.⁶

⁶ Linda Park-Fuller, 'How to Tell a True Cancer Story' in *Text and Performance Quarterly*, 28, 1/2, 2008, p. 180.

Park-Fuller then goes on to list these narratives and explain their usefulness. While she was correct in saying that I had not considered these other works, my ignorance around them — and my exclusive response to more popularly-legitimated texts — functions in a way which may demonstrate the power or hegemony of those popular texts and narratives as I had not even realised that such politically-engaged or insightful text existed. Although I believe that *BALL* does hit upon political and social themes outside my own experience, this was not my central concern in the text nor was it the central concern for the majority of spectators to the work, instead focusing on highlighting ironies inside of survivorship narratives and, in fact, producing my own kind of survivor story.

In reviews of cancer narratives, and in marketing of books and films that take cancer as their central concern or plot point, similar concerns and claims have been made, and — as I demonstrate below — refer to a canon of cancer work that was referred to, but never named. In particular, the word *unsentimental* is often employed when reviewing books or films about cancer, as if distinguishing *this* *unsentimental* work from *those* *sentimental* works about cancer. Reviewers note, for example, that Margaret Edson's play *Wit* is *unsentimental*, as are Anatole Broyard's memoir *Intoxicated By My Illness* and Lucy Grealy's *Autobiography of a Face*.⁷ More than a typical marketing ploy to demonstrate the originality of a given piece of work, the marketing distinction of a work being *unsentimental* both distances the new cancer story from the old while simultaneously degrading the referent narratives. We may not know the

⁷ Howard Rosenberg, 'HBO's 'Wit': A Touching, Unsentimental Look at Dying' *LA Times*, 23 March 2001, <<http://articles.latimes.com/2001/mar/23/entertainment/ca-41467>> [accessed 25 December 2011]; Anatole Broyard, *Intoxicated by My Illness: And Other Writings on Life and Death* (New York: Fawcett Columbine, 1992), front cover; Lucy Grealy, *Autobiography of a Face* (Boston: Houghton Mifflin Company, 1994), back cover.

names of these other narratives such reviews are speaking about, but we know one thing that they are: sentimental.

In *The Emperor of All Maladies*, Mukherjee identifies what might be the starting point of sentimentality (and a generalised sentimentality at that) and its deployment in cancer conversations. Mukherjee recalls the creation of ‘Jimmy’, who was actually a child with leukaemia named Einar Gustafson.⁸ In hopes of raising the profile of leukaemia research and to raise funds for clinical trials, oncology researcher Sidney Farber and philanthropist Bill Koster changed Einar’s name to Jimmy and convinced a popular radio programme to broadcast from his hospital room. In the eight minute radio piece, Jimmy is interviewed about his favourite baseball players (this was clearly by and for an American audience) after which point all of these players from the Atlanta Braves (his favourite team) walk into his bedroom and introduce themselves to him. After singing “Take Me Out to the Ballgame” (the unofficial baseball theme song), the broadcaster disconnected the remote link to the hospital and stated his very short plea for donations: “Let’s make Jimmy and thousands of boys and girls who are suffering from cancer happy by aiding the research to help find a cure for cancer in children”.⁹ The baseball stars, the sick children, the singing, and the plaintive call for donations was completely new at this moment in 1948 but was part of a strategy to humanise cancer patients — especially children with cancer — in hopes of drawing more money towards research. Today, listening to the radio broadcast (available on the Jimmy Fund website) still inspires emotions, and it is hard to imagine how listeners, hearing about cancer from the first time, might have reacted to such an account. Mukherjee demonstrates that,

⁸ Siddhartha Mukherjee, *The Emperor of All Maladies* (London: Fourth Estate, 2011), p. 98.

⁹ ‘The Voice that Launched the Jimmy Fund’, *Jimmy Fund*, <<http://www.jimmyfund.org/abobroad/media/broadcast.mp3>> [accessed 2 February 2012].

after \$231,000 (in 1948) was raised in months, such a tone was efficacious in communicating about cancer.¹⁰ While narratives about cancer — as I will demonstrate — come with different goals than cancer fundraisers, it is very possible that the Jimmy Fund broadcast may have jumpstarted the now-seemingly-natural combination of cancer story with sentimental tone.

The research I conducted on cancer narratives — fictional and non-fictional accounts, but not journalistic pieces as with the Jimmy Fund above — began through a consideration of cancer movies, in hopes of understanding what made a cancer narrative tick and trying to get a feel for what this sentimentality looked like in its most popular form. Viewing cancer narratives through the lens of Vladimir Propp's *Morphology of the Folktale*, I was interested in identifying the criteria which make a cancer story a cancer story, similar to how Propp went plot point by plot point to demarcate and classify certain types of Russian folktales. Like Propp, who defines folktales as those stories without a specific origin that are present in many locations, my investigation into The Cancer Narrative took as given my visceral, bodied experience that the origin of cancer stories (and a given tone for cancer stories) was impossible to pin down and yet pervasive.¹¹ Mukherjee traces the usage of the word cancer from its appearance in Ancient Egyptian texts and then in Greek — where the word originated — but also identifies how the illness mostly disappeared from historical texts until the 1800s thus making the contemporary cancer narrative a relatively new phenomenon and one with an ad-hoc, as opposed to well-documented, history.¹² Propp's folktales, also created in an ad-

¹⁰ Mukherjee, p. 99.

¹¹ Vladimir Propp, *Morphology of the Folktale*, trans. Laurence Scott. 1968 (Austin: University of Texas Press, 1968). p. 16.

¹² Mukherjee, p.41.

hoc manner, were stories which did not share a singular origin and also contained quasi-interchangeable parts, much as I find cancer stories to do: plot points included diagnosis, revealing cancer to loved ones, treatment, chemotherapy, hair loss, vomiting, attempts at humour, acceptance of fate and survival (or death). Although presumably the first and last plot points had to remain consistent, all that happened in between was negotiable, but more than likely were present in some order.

The doctor feels a lump at Emma's routine check-up ("You have a lump in your armpit") and suddenly *Terms of Endearment* (1983) becomes — 75 minutes into the 130 minute film — a movie about cancer.¹³ Brian Piccolo coughs 45 minutes into *Brian's Song* (1971) and it instantly becomes a movie about cancer.¹⁴ In *The Bucket List* (2007), the characters find out within the first five minutes that they have terminal cancer: Morgan Freeman's character (a well-meaning mechanic) receives a phone call from his doctor (who we can't hear), drops his cigarette and we know that this is a movie about cancer.¹⁵ He probably has lung cancer. In the next scene, an emotionally distant health insurance company owner, played by Jack Nicholson, coughs blood into an expensive handkerchief. We know that this is a movie about these two men's cancers and how the disease will awaken Nicholson's 'inner humanity' by teaching him the value of things money cannot buy. Propp's analysis of folktales begins with how stories become 'about' a given topic:

[A] part of a tale is selected (often haphazardly, simply because it is striking), the preposition 'about' is added to it, and the

¹³ *Terms of Endearment*, dir. James L. Brooks (Paramount Pictures: 1983).

¹⁴ *Brian's Song*, dir. Buzz Kulik (Screen Gems Television: 1971).

¹⁵ *The Bucket List*, dir. Rob Reiner (Warner Bros: 2007).

definition is established. In this way a tale which includes a fight with a dragon is a tale ‘about fights with dragons’.¹⁶

While it might be reductive to describe these films as being simply ‘about cancer’, the power of the word, as a cultural signifier of death and destruction, ensures that once Emma or Brian coughs, the trajectory of the film shifts dramatically and unexpectedly. While *Terms of Endearment* attempts a broader investigation about illness and communication — with powerful scene featuring a lunch between Emma and four women who talk about everything *except* for the fact that she’s dying of cancer — *Brian’s Song* allows cancer to be the prevailing and exclusive theme, perhaps because of the severity of Brian Piccolo’s cancer or because of the even poorer communication around cancer in 1971 when the film was made. In *Brian’s Song*, the word cancer is said only twice. The striking nature of cancer may unfairly make a story ‘about cancer’, a point similarly made throughout Propp’s extensive narrative analysis in relation to folktale themes like dragons, princes or amulets. However, because of the history and cultural significance of cancer (which has a culturally constructed world around it much different than the dragons discussed in *Morphology* although may share themes of unexpected beasts, heroes, etc) the dropping of the word or themes of cancer, from an audience perspective, cannot help but make the story shift focus to the deadly potential of the disease — with the years of ‘the big C’ still fresh in most people’s minds.

In a scathing critique of *The Bucket List*, American film critic Roger Ebert (who became famous for his Two Thumbs Up system) responded to the danger of making a film ‘about cancer’, particularly when the cancer feels starkly removed from reality. Or, as Ebert writes, when the cancer “is nothing like cancer”:

¹⁶ Propp, p. 7.

[T]here is nothing like a serious illness to bring you to the end of sitcom cliches. I've never had chemo, as Edward and Carter must endure, but I have had cancer, and believe me, during convalescence after surgery the *last* item on your bucket list is climbing a Himalaya. Your list is more likely to be topped by keeping down a full meal, having a triumphant bowel movement, keeping your energy up in the afternoon, letting your loved ones know you love them, and convincing the doc your reports of pain are real and not merely disguising your desire to become a drug addict.¹⁷

For Ebert, *The Bucket List* seemingly employs cancer — the cultural mythology and the sympathy that inherently comes along with it — to bring the audience further towards an emotional, cathartic release without actually filling the story with truthful emotional or medical content, as described above. The highly loaded nature of the word cancer does the work for *The Bucket List's* creators, and this action is what Ebert finds reprehensible. Cancer — perhaps because its own oversimplification in literature and film as a signifier solely for death — creates a much clearer picture for audiences than illnesses such as multiple sclerosis or meningitis, but this clear picture might still be inaccurate. Roger Ebert, who had his jaw removed as treatment for thyroid cancer and agreed to be photographed while nearly unrecognisable, uses his own experience as evidence and brings to the fore how use of cancer can be protected and policed, in a manner which felt very similar to my point of view when writing *Other Funny Stories About Cancer*. Although Ebert's review plays into ideas of a singular cancer experience (and that *The Bucket List* can't be accurate because *his* was not like it) his writing more importantly protects cancer from being easily commodified, cuddly, and inaccurately portrayed. It does this by charging *The Bucket List's* producers with naively creating a story 'about

¹⁷ Roger Ebert, 'Review of *The Bucket List*', *Chicago Sun-Times*, 10 January 2008, <<http://rogerebert.suntimes.com/apps/pbcs.dll/article?AID=/20080110/REVIEWS/801100301>> [accessed 26 December 2011].

cancer' which engages with the easily-recognised tropes, such as vomiting and baldness, but none of the more subtle medical or psychological realities.

In *BALL*, I attempted to play with the idea that a story featuring cancer was, inherently, a story about cancer. In the opening of the performance, to the audience, I announce that “I sometimes forget to tell people that this is a story about cancer, or at least, sort of about cancer, but I don’t die at the end”, as if fighting against simple categorisation, but more so, fighting against the sentimental tones of cancer that are present in work like *Brian’s Song* or *Terms of Endearment*.¹⁸ If a story was ‘about cancer’, it would seemingly have to include all of these sentimental themes — the long stares, the loving embraces, the teary goodbyes perhaps well suited to television and film — and I knew that *BALL* would not contain those aspects. But there was one main difference even from the outset between what I was writing and the stories of both of these films: I didn’t die at the end of my story. Perhaps it’s easier to write a story that’s unsentimental, humorous or heroic when cancer is survived. Jackie Stacey, in her introduction to *Teratologies: A Cultural Study of Cancer*, nicely captures how the two trajectories of cancer narratives can progress, writing that “If the person with cancer has lived to tell the tale, the story is often a heroic struggle against adversity,” whereas “If [...] the person with cancer dies, the story told is one of loss and of pain, but also tends to be a celebration of their courage and dignity”.¹⁹ While *BALL* plays against ideas of heroics inherent in cancer survivorship, it was written in response to this other strand of dignified narratives in which the central figure dies.

¹⁸ Brian Lobel, *BALL* in *Text & Performance Quarterly*, 28, 1/2, 2008, p. 160.

¹⁹ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (London and New York: Routledge, 1997), pp. 1-2.

There's a cough, or a faint, and thus starts the story being 'about cancer'. This does not only hold true in Hollywood, but in contemporary performance as well. In Annie Sprinkle's *Exposed: Experiments in Love, Sex, Death and Art* (2006), Sprinkle and partner Beth Stephens, in their disarming DIY performance style, explore their marriage, politics around same-sex marriage in the United States and their attempts to have a child.²⁰ After discussing all the various types of stress in their life at the beginning of the second act, Beth offers Annie a massage. When she begins, Annie straightforwardly takes out her breasts and says "These are my breasts. How many of you have seen them before?" As an audience, we watch, with both Beth and Annie facing forward, Beth massaging Annie's shoulders and breasts which have been such a significant part of her personal history as a former porn star and prostitute. Her breasts have also been a significant part of performance history, as she told the audience, highlighting their appearance in *Bosom Ballet*, a piece which she has performed quite regularly throughout the past 15 years.²¹ The caressing becomes more sexually charged and when the audience — not unused to seeing nudity or sex in Sprinkle's live performance — prepares for something of a more erotic or sexual nature, Sprinkle touches her own breast with concern, rips off the wig she has been wearing to reveal a bald head, and, suddenly, this becomes a performance 'about cancer'. A breast touched with concern plus hairlessness equals cancer; the combination of those two loaded signifiers could rarely add up to anything else. But before audience members have the opportunity to be too upset or nervous or for too long if they are so

²⁰ Annie Sprinkle and Beth Stephens, *Exposed: Experiments in Love, Sex, Death and Art* (2006).

²¹ 'Annie Sprinkle's Bosom Ballet', *Annie Sprinkle*, <<http://anniesprinkle.org/projects/archived-projects/annie-sprinkles-bosom-ballet/>> [accessed 22 January 2012].

inclined, they see Annie Sprinkle alive in front of them, so they know that this story will end as a survivorship story. Each audience member goes through their own experience of potentially feeling sad, tired or needing to prepare for the long slog through chemotherapy, radiation or depression, but for each spectator, they know there will be a recovery, a victory, a triumph for Annie, and for Beth.

Although the set-up is more provocative than its *Bucket List* or *Terms of Endearment* counterparts, the instant flip into the work being about cancer happens as quickly, intensely and clearly as the others. And perhaps this shift of focus is not only a live performance or filmic trope. Perhaps the revelation of cancer is a quality that, even if one avoids essentialising particular experience across individuals, *is* essential to the cancer experience, or at least how it is experienced in today's medicalised society. Because of the physical nature of cancer, in which a malignancy slowly grows unnoticed by the body's own immunities, affirmative diagnosis only comes after medical test results apply the word cancer to a given group of symptoms or, as Stacey writes about this moment: "The narrative that emerged gradually organised physical sensations into a temporal sequence with causative effect."²² This is quite different from most other illnesses, where symptoms are more clearly noticed or visible to the naked eye. This diagnosis comes, more often than not, in the office of a doctor who has (before giving the patient the results) already charted out a course of action for that patient, a process vividly recalled by Mukherjee when describing his diagnosis of his patient Carla.

I ran through the list of tests that would be needed on her blood and mentally rehearsed the conversation I would have with her. There was, I noted ruefully, something rehearsed and robotic even about my sympathy.²³

²² Stacey, p. 4.

²³ Mukherjee, p. 3.

The word cancer is said and immediately followed by more tests and a complete change in lifestyle. This is, at its most disempowering, the moment in which medical professionals can employ their exclusive knowledge of medical science as rationale to take more tests *now* or to remove a breast *now*, accompanied by the (usually unsaid) ‘Or else...’

It was this moment of ‘Or else...’, when a surgeon drew on Jo Spence’s breast that started her work on cancer and patient empowerment which was created in response to the top-down, expertise-laden approach she experienced in hospital.²⁴ Audre Lorde talks about this pressure even after the recurrence of her cancer, writing:

Now that the doctors here have decided I have liver cancer, they insist on reading all their findings as if that were a *fait accompli*. They refuse to look for any other reason for the irregularities in the x-rays, and they’re treating my resistance to their diagnosis as a personal affront. But it’s my body and my life and the goddess knows I’m paying enough for all of this, I ought to have a say.²⁵

Spence and Lorde both wrote about their personal interventions in these processes — either engaging in homeopathic and alternative therapies or refusing chemotherapy altogether as in the case of Lorde. Because of the very nature of the illness and how it is usually diagnosed through medical conventions, the shock and sudden shift to the story/narrative being ‘about cancer’ is not surprising. With Spence and Lorde, the theoretical and political work they were engaged with (feminism, post-colonial studies) framed their understanding as to what was happening with their body and how, as Frank writes about Lorde, “modernist medicine claimed the body of its patient as it

²⁴ This is particularly highlighted in her series of photographs published in Jorge Ribalta, ed., *Jo Spence: Beyond the Perfect Picture* (Barcelona: Museu d’Art Contemporani de Barcelona, 2005), p. 268-280.

²⁵ Audre Lorde, *The Audre Lorde Compendium: Essays, Speeches and Journals*, (Pandora: London, 1996), p. 290.

territory” in a manner which clashed with her post-colonial understanding of subjectivity.²⁶ Adding an intense layer of perspectives to an already difficult moment, the shifting of the story of the body into being about a cancer body is even more so heightened when the patient is aware of her own place inside critical discourses.

The sudden move to surgery and procedure is not always traumatising, as exemplified by Stacey’s own experience with a doctor who had delayed her diagnosis with cancer, writing “His female superior, who finally made a correct diagnosis and insisted on emergency surgery on a Sunday, becomes an angel rescuing me from imminent danger”.²⁷ For Stacey, the instant course of action seemed to provide assurance that the problem was being recognised and dealt with as a matter of priority. For myself, because I was given a very positive prognosis in which a prescribed course of chemotherapy would ultimately, more-than-likely, result in success, I felt less shocked by the suddenly overwhelming nature of medical information. This, however, should not suggest that the shift was not abrupt and difficult. *BALL* was written just as it was experienced, with diagnosis as the very first line of the show. Responding to an unseen doctor’s diagnosis, the opening line of *BALL* acknowledges the moment of, as Sontag would describe, the moment of shift into the “world of the sick”: “Problematic?” is the opening line, and all that is said of the diagnosis, as if nothing came before and no additional context is needed.²⁸

In March 2010, I created a short performance, entitled *An Appreciation*, which attempted to explore, specifically, this abrupt transition between not

²⁶ Frank, p.10.

²⁷ Stacey, p. 4.

²⁸ Lobel, Brian, ‘BALL’, *Text & Performance Quarterly*, 28, 1/2, 2008, pp. 160-177.

having cancer and having cancer in a playful manner, and to draw attention to the moment in which a narrative becomes a story ‘about cancer’ in an unexpected way . Drawing inspiration from Annie Sprinkle’s *Public Cervix Announcement* (1990) I invited five audience members onto the stage at Duckie (held at the Royal Vauxhall Tavern, which regularly hosts queer club and performances in London) at 11pm on a Saturday night and asked them to appreciate my genitals with their hands. I provided the definition of ‘appreciation’ as both casual (to recognise the quality, significance or magnitude of a thing) and medical (to recognise the quality, significant or magnitude of a lump or bump) and told them that we would be exploring the latter definition in this performance. I provided each volunteer a latex glove and a shot of whiskey. When they were finished, they were then asked to write a one-word description on a note card, which was then placed face down. Without any context of illness or bodily non-normativity, *An Appreciation* appeared, at first, as a trashy or provocative live art piece which fit the usual Duckie bill which ordinarily features alternative cabaret acts. Turning my face back to the audience, fully dressed, the text began simply:

In the eight years since I had my right testicle removed, I’ve pretty much forgotten what it feels like to have two testicles. This is a perspective I’m completely comfortable with and one, if I’m honest, that developed without too much resistance. I never realised what it felt like to have two testicles — until, of course, I realised that one was cancerous...²⁹

By dropping the word cancer, my hope was to instantly flip the meaning of the touch from something funny and flippant, to something sombre and reflective. Suddenly, this was a story ‘about cancer’. After each short paragraph of text, written about how I’ve negotiated my body’s slight non-normativity through the

²⁹ Brian Lobel, ‘An Appreciation’, *Vimeo*, <<http://vimeo.com/10520311>> [accessed 6 January 2011]. Will be available on *Cancer Cancer Cancer* (London: Live Art Development Agency, 2012) from April 2012. The link is provided for immediate reference.

years, I read out one of the notecards written before the audience or volunteers knew that I had one testicle and a history with cancer.

My aim here was to silence and focus the room in a way that felt unexpected, much like a diagnosis. While I think the power of cancer to silence is problematic, as will be explored later in this chapter, it is also worthy of exploration as its own topic. And to watch 200 drunk gay men (with a handful of lesbians, straight women and others) actually become silent was a particularly meaningful experience for me as a performer as the Duckie crowd at 11pm can be particularly boisterous. The silence in the audience that night — which is particularly noteworthy on the documentation of the work — seemed to evidence, in perhaps the strongest way I had experienced, the power of the word cancer to shift the energy and mood of an audience almost instantly. The performance ends with a recitation of all five volunteer-generated terms, and asks audience members:

If you'll humour me, for another 20 seconds, close your eyes and try to imagine yourself eight years ago. What you looked like, what your body felt like. How it felt to touch someone, and how it felt to be touched. Even if I could remember what it felt like to have two testicles, enough else has grown since then. Bodies change a ridiculous amount over time; I think I'm just starting to appreciate that.³⁰

While the performance ends on a 'touching' or sentimental note, I hope it does so by engaging audience members with a reflection on their own lives, instead of just asking them to engage in a catharsis based on someone else's trauma. That said, though, it may also be that since writing *BALL*, I'm more comfortable with the power of sentimentality as a performative tool. The transition between

³⁰ Words from audience members include: warm, firm, squishy, vulnerable, fan-fukin-tastic, friendly, fabulous, fleshy, hard, a bag of offal, potential, hot, saudavel (healthy), symmetrical, pretty, soft, immense, sane, singular, rubbery, weird, bumpy, unconvincing, globular, sweet man, ebb, ovular, heavy, comforting, abrasive, uranus, uniqueness, thick, unique, spring-apricots among approximately 300 more.

the playfully sexual tone of the introduction into the sentimental tenor of a conversation about cancer, as a trope, felt like a productive strategy through which to negotiate that classic shift which begins when the breast is touched with concern, the wig is pulled off, or the future patient coughs uncontrollably.

Returning to the case of Sprinkle and Stephens' *Exposed*, the shift to the story becoming 'about cancer' is marked by a radical change in form, much as previously discussed in the work of Jo Spence in Chapter 1. What had been light and playful — even when talking about marriage equality and topics about which the performers felt strongly about — becomes silent and sombre. In an earlier part of the performance, Stephens had shown a slideshow of her previous work, happily narrating her ideas and the people she had met along the way. A similar slideshow runs after the baldness is revealed, but this time, the slideshow proceeds without narration. The pictures of Sprinkle's cancer tell us all that we think we need to know, perhaps tapping the audience's knowledge of cancer and cancer narratives which lived in the same reservoir that I felt I was rebelling against in 2002, without having a specific narrative in mind. The wordless slideshow represents the first of the major changes to *Exposed*, and is followed by a narrative, which reflects on the broken nature of the illness experience. Speaking for the first time in poetic, searching questions, the two women plaintively speak about the experience from an emotional, as opposed to plot-driven, perspective. Both Sprinkle and Stephens recite "I hardly recognise myself. I can't trust myself to finish a sentence. I'm not all here. I can't remember what I'm supposed to say. Where's my energy? I thought this happened only to other people". Through this change in language, Sprinkle and Stephens demonstrate a change in understanding the world and a necessary, accompanying change in performance form. All of what had been discussed

previously — the love chakras, the marriages, the politics — suddenly dissipates, as if unable to hold the same emotional or dramatic weight of the cancer experience.

When the story becomes ‘about cancer’ for Sprinkle, the shift in performance style is coupled by an exclusive focus on the specifics of cancer treatment demonstrate that cancer sets a precedent for Sprinkle and Stephens which must be immediately addressed. Because of the aforementioned nature of cancer — with which the label of the disease marks a complete reconfiguring of the body’s self-understanding — there is a first-time-ness to diagnosis which appears over and over again inside cancer narratives. As Elaine Scarry wrote about embodied perspective in *The Body in Pain*: “To have pain is to have certainty; to hear about pain is to have doubt.”³¹ While cancer patients do not, upon diagnosis, normally experience pain as Scarry describes in relation to torture (pain will come later if prescribed surgery, chemotherapy or radiotherapy), the certainty at diagnosis is one in which the word cancer defines (in both the present and future tense) how one sees their own body — and their certainty tells them that this is really happening. For the individual being diagnosed with cancer, the certainty of this moment may be the impetus for the shift in style, in narrative, and in self-knowledge. The writing of the narrative — as with *Exposed* — may attempt to make sense and a through-line beyond this shift, as Stacey writes: “When something unexpected occurs, such as illness, the scripts need rewriting, but normally the shock of the experience can be partly absorbed by the telling of a new story”.³²

³¹ Elaine Scarry, *The Body in Pain: Making and Unmaking the World* (Oxford: Oxford Paperbacks, 1988), p. 13.

³² Stacey, p. 9.

The shock of an illness, as Stacey describes, such a cancer diagnosis, is not, however, a precedent outside an individual's own body, or to those outside the person's immediate contacts, thereby putting the embodied experience of illness/diagnosis at odds with the outside world not currently experiencing such a precedent. While one's own bodily knowledge shifts drastically, with doctors giving new terminology to embodied experience that has caused until-now-undefined symptoms, the world outside of one's own body has not shifted. Millions of people are diagnosed with cancer every year, and the process is not unknown. But for the individual experiencing illness, a complete re-envisioning of their body, and their relationship to the outside world shifts immediately and intensely. While this could be said for many events — disabling accidents, pregnancy — there is something about the enigma of cancer whose diagnosis (when words give order to invisible symptoms) radically shifts an individual's understanding of the body's capabilities. But the world, outside the patient's immediate care community, continues rotating on its regular axis.

There is a political dimension to this shift in which individual cancer patients view their own diagnosis as a shift in understanding the world and the world's potentials. If nearly half of the people in the world get cancer, it cannot be a surprise that people may be diagnosed with cancer, much like it's not surprising or shocking (from a cultural perspective) for people to find out that they have debilitating arthritis, diabetes or heart disease. And yet, it is consistently seen as a precedent as if one's complete understanding of the world has shifted. Employing the legal use of the word precedent, it is as if all future decisions (on life, career, politics, religion) will be somehow based on this moment. Kairol Rosenthal, a patient advocate, published her book of interviews with young adults with cancer titled *Everything Changes*, an oft-heard phrase

related to diagnosis, and one that repeats like a chorus throughout her interviews.³³ Everything Changes, and yet, it doesn't. Perhaps the most intriguing paradox of a cancer diagnosis is the unique experience of an individual and the simultaneous ubiquity of cancer diagnoses. For each patient whose life is changed when being diagnosed, there is a team of hospital administrators who are simply working to register a new patient.

Cancer and Precedent

The idea of cancer as bodily precedent, which will determine and influence all that comes after it may have correlations with performance work which chooses, as its topic, a significant historical precedent, such as the Holocaust. This point is not uncontroversial, but many have written on similarities and differences between major historical events and major personal events and a correlation in the all-encompassing experience of a nation and the all-encompassing experience of a body. "Cancer is not a concentration camp,"

Frank writes

but it shares the quality of annihilation: it negates the possibility of life outside and beyond itself; it subsumes all living. The daily life of a patient becomes so intensely preoccupied with his or her illness that the world fades away.³⁴

In 2007, the Urwintore Theatre company from Rwanda produced an adaptation of Peter Weiss' *The Investigation* at the Young Vic Theatre in London. *The Investigation*, written in 1968, was Weiss' response to the Frankfurt Process in 1964 — one of the final Nazi war crime trials — and attempted to find an

³³ Kairol Rosenthal, *Everything Changes* (Hoboken: John Wiley & Sons, 2009).

³⁴ Arthur W. Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: The University of Chicago Press, 1995), p. 98.

aesthetic means to address the mass killings.³⁵ Weiss is not alone in describing the aesthetic precedent necessitated by the Holocaust. Jean-François Lyotard, responding to the reality ushered in by the Holocaust wrote:

The facts, the testimonies which bore the traces of here's and now's, the documents which indicated the sense or the sense of the facts, and the names, finally the possibility of various kinds of phrases whose conjunctions makes reality, all this has been destroyed as much as possible.³⁶

The impact of the Holocaust went beyond the physical decimation of lives and property and, because of its scale destroyed an emotional and rational understanding of the world and all that had come before. The text of *The Investigation*, an edited transcription of the trial, is credited with being the first documentary theatre performances and was an attempt to create a new kind of performance. Weiss stated that after the horrors of the Holocaust, narrative theatre could not capture this new reality.

Urwintore's production of *The Investigation* employed an edited, but similarly structured, transcription of the trial, which more than a conventional representational drama, hoped to capture a new (post-Holocaust) reality. Urwintore's production invited spectators to realise that this unprecedented, horrifying event — about which many invoked the phrase NEVER AGAIN — had, in fact, been repeated in history in Rwanda in 1994. Even further, Urwintore's *Investigation*, through its re-creation of a pre-existing text about the Holocaust, rails against those who stayed silent during the Rwandan genocide by reminding them that this precedent has already been seen and that the West's ignorance about the horrors of genocide is simply inexcusable. If people

³⁵ Olaf Berwald. *An Introduction to the Works of Peter Weiss* (Rochester: Camden House, 2003), p. 23

³⁶ Jean-François Lyotard quoted in Vivian Patraka, *Spectacular Suffering: Theatre, Fascism and the Holocaust* (Bloomington: Indiana University Press, 1999), p. 86.

had stayed silent during the Holocaust, using as an excuse that they could not believe that such rumoured horrors were true, such an excuse was no longer possible — such horrors had not only been rumoured before, but had now been well-documented and disseminated.

Although the death of millions of Europeans is considered by some as something which destroys — as Adorno suggested — the ability to write poetry or create art, Urwintore's production addresses worldwide inaction and the double standard which says that NEVER AGAIN applies to only certain people. Urwintore, however, never said any of this on stage — their production was sleek and quiet, drew no political parallels to Rwanda aside from the statements in marketing material and cast biogs that the cast were Rwandan. In the programme for the production, however, the point is sharply driven home saying, "If another genocide has been perpetrated after Auschwitz, it is because the conditions of such a crime were still to be found in the world".³⁷ The conditions include not only include violent xenophobia and bigotry, but also inaction and ignorance that such horrors are still possible. Dorcy Rugamba, director of Urwintore, even in this text has chosen not to position himself as a Rwandan man. Much like the previous description of Annie Sprinkle's discovering her breast cancer (the bald head and the breast touched with concern), a production featuring Rwandan performers and conversation about genocide (even using German or Jewish names) equals, for many in a British audience, a performance 'about the Rwandan genocide'. While Bobby Baker spoke out against the marketing team constantly linking her to her mental illness, and Koppers railed against Croce for her flattening of all people with terminal illness to be defined by their physical realities, with *The Investigation*,

³⁷ Production notes from *The Investigation*, dir. Dorcy Rugamba.

Urwintore is using the loaded signifiers of themselves as Rwandan citizens and a conversation about the Holocaust to encourage audience members to create the linkages for themselves.

What Urwintore's production of *The Investigation* lends to this conversation about precedent and illness is that a singular perspective about an individual's embodied experience remains difficult to enforce, and that even though a precedent feels real and unique to the individual, there still remains a serious divide between the individual and society at large, and a claim of something being unprecedented may fail to produce the expected impact on society. Although Weiss, and many other commentators, made the artistic and political claim that the Holocaust was unprecedented, Urwintore's production demonstrates that this claim of unprecedentedness is not/was not politically viable, not useful enough to convince people to get involved when they saw something similar happening again. With illness, there is no claim that understanding one's bodily precedent can prevent another's illness (although this may be the rationale for some anti-smoking campaigns) this conversation serves to highlight the potential problems associated with making claims to an occasion being unprecedented. People with and without cancer may be badly served by the linguistic walls (and claims about its unprecedented nature) that are put up around disease, after which a diagnosis shifts a patient's entire reality. Very few equally harmful and serious diseases carry this kind of power, and the exceptionalism promoted about cancer seems only to make the often-inevitable shift from not-having-cancer to having-cancer all the more traumatising for individuals.

The shift from not-having-cancer to having-cancer and the accompanying shift in relationship to the world may be as much a part of diagnosis as hearing

new biomedical terminology. In this narrative, the diagnosis is a process which starts from ‘shift in reality and relationship to the world’, and is quickly followed by shocking silence (the previously mentioned slideshow in *Exposed*), medical terminology, attempts at humour (Sprinkle and Stephens compare their treatment to a fashion show), and, most importantly, if appropriate, a statement of survivorship: “My prognosis is excellent” Annie proclaims. “According to statistics I have just an 8% chance that the cancer will recur before the end of our seven-year project”. The numbers and statistics also seem essential to conveying the cancer experience — particularly for survivors — so that as an audience we can know just *how* positive to feel, *how* far the survivor came, or *how* dire the circumstances were. The numbers help an audience frame their reactions, and give clues to audience members as to the stakes of the situation. The numbers can make us guffaw or fill with pride, but they also don’t have realistic correlates. We don’t live 60% alive, or even 95% alive. We live, or we die. If we know that alpha fetoprotein numbers (a marker of potential cancerous growth) are meant to test at a level <5 , who knows what it means to say they are 150,000? Does it mean it’s really that bad, or is it just on another kind of scale? What does it mean to say that we have a alpha feta protein level of 32,000?

The numbers, in fact, tell an audience nothing. They have little correlation to lay language and it is impossible to draw conclusions from them as most don’t understand the scaling. But we do know one thing: Big numbers — if we’re told that big is bad — are scary. And the bigger it is, the worse it is. Conversely, small numbers, when they are describing recurrence chances, are good, if we’re told that small numbers are good. For Sprinkle and Stephens, the ending of the part of their performance ‘about cancer’, seems succinctly closed

with this statement of low chance of recurrence. Although people are not ever 8% or 92% alive, audience members can feel secure knowing that perhaps Sprinkle dodged this cancer bullet, can see evidence of her physical health in her live performance and presence, and can be comforted enough to move towards the end of the performance, which comes moments later.

In the example of *Exposed*, live performance makes explicit the context of the cancer story: the audience knows immediately that this is a narrative in which the protagonist lives. As solo performance (Sprinkle and Stephens, although a duo, are most known through the solo performance genre) is most often performed by the work's originator, the genre's known commitment to autobiographical transparency (or, if not transparent, a playful take on ideas of autobiographic transparency) often confirms that the originator's story is the one that is being told. Because it is the originator telling the story, an audience can be immediately comforted to know that this cancer story, although potentially harrowing, will have a 'happy ending' because the spectator, as noted by Heddon, is "confronted by the physically present self" of the performer.³⁸ While such a pattern exists in non-fiction written work as well (marketing, book jackets, reviews or book tours will undoubtedly inform the reader whether the originator is alive or dead before they begin), the live performance even more so confirms the presence of a living (surviving) body. Because an audience knows, from the beginning of Sprinkle's section on cancer, that this is a survivor story, they can — if the cancer narrative is as socially-constructed an idea as I have discussed it to be — feel free to prepare themselves for a survivor story to be told.

³⁸ Deirdre Heddon, *Autobiography and Performance* (London: Routledge, 2008), p. 27.

When I describe Sprinkle's performance as fitting the pattern of a cancer narrative, this critique is not meant as criticism. As discussed previously, there may be pieces of the cancer experience that are 'essential' to the cancer experience and not because everyone is diagnosed in the same way or with the same cancer. Thinking that there may be an essential cancer response may derive from the fact that language around illness (used by doctors, patients, nurses, hospital administrators and beyond) is so institutionalised, codified and taught that the response from patients — and patients who eventually create work about the experience — derives from this same limited set of impulses. This strict linguistic code, in part, may be an outcome of medical training such as the OSCE (Objective Structured Clinical Examination) tests, currently given to all medical students, which dictates suitable language for examinations. By making objective the process of examining and diagnosing patients, and assessing medical students based on the presence or absence of certain terminology, medical education runs the risk of flattening inter-patient differences. Instead of taking a patient-centred approach to diagnosis, OSCE exams may be responsible for both denying patients the most humanising or personalised medical care, and may also be promoting a strict linguistic code for how cancer can be diagnosed and discussed. While programmes like London-based Clod Ensemble's *Performing Medicine* work inside medical schools to encourage students to be more responsive to patients, the tradition of a strict linguistic code and regimented behaviours — as may be exemplified by Sprinkle and Stephens' *Exposed* — is deeply ingrained in medical education and continues to predominate.³⁹

³⁹ *Performing Medicine*, <www.performingmedicine.com> [accessed 16 November 2010].

About the Bike: Lance Armstrong and Me

Reading *It's Not About the Bike* (2000), Lance Armstrong's first cancer survivor book, was a task I had put off for many years. It wasn't that I didn't have access to the material — in fact, three copies of the text were placed on stage during the first staging of *BALL* in 2003, each copy of the book had been given to me by well-meaning family friends in 2001. They each considered it essential reading while undergoing cancer treatment. I judged the book by its cover and no spines were ever cracked, until 2010, when this research brought me to understand that, in order to critique the cancer narrative story as exemplified by Armstrong, or to reflect on what (hopefully) made my work different, I would need to understand its origin. When considering my own experience of not-reading *It's Not About the Bike*, I find myself forced to think about the attraction of the book to many, as Armstrong's writing became a wildly successful memoir and platform for his LIVESTRONG campaign, which was one of the most successful cancer campaigns in history. When considering the reviews which are featured on the cover, phrases like "awe-inspiring" and words such as "courageous" and "inspiration" demonstrate that it is his triumph over mortality which is the main marketing strategy by the publisher. In this way, *It's Not About the Bike* instantly identifies itself as a survivorship story — had it been anything else, it would have assuredly featured more sombre colours and adjectives like "unsentimental" or "heart-breaking". While I was reading it to see how Armstrong's view on cancer differed from or was similar to mine, I can imagine most people read it to get the inside scoop about this international sports star, and to be moved by his triumphant return from near-death to being the winner of gruelling sports competitions. I imagine a high percentage of the world's cancer population (those currently in treatment, post-treatment, or otherwise

affected by testicular cancer in particular) reading the memoir, either encouraged by others for its inspirational quality, or simply because so many people gave them copies of the book, as I had experienced.

While Armstrong's fame more than likely prompted the writing of a memoir, his experience of creating a narrative from the experience of illness may share similarities with other writings and performances. Much like the survivorship story in *Exposed, It's Not About the Bike* celebrates the completion of a journey and educates an audience about cancer and attempts a broader conversation around illness. While *It's Not About the Bike* concretises this process by concluding the book with a chapter on the LIVESTRONG campaign, Sprinkle's and Stephens' *Exposed* and *BALL* promote self-examination and injects the cancer story with language about breaking taboos and silence around cancer. The inspiring force behind stories with a bereavement trajectory — like *Terms of Endearment*, *Intoxicated by My Illness* or even *The Bucket List* — seem to have been created in an attempt to create catharsis (in its classical Aristotelian sense of being a positive purging of emotions) for both their creators and audiences. The invocation of seemingly-sentimental tropes appear in the function of such a reaction and, while different than the driving factor behind the creation of survivorship stories, feel identifiable as artistic goals.

The telling of the story is a very serious part of process of understanding one's illness and is often how I first talked with people after a performance of *BALL*. Stories about fathers with cancer, friends recently diagnosed or teary questions at Q&As often began with this claim that people did not know 'which way was up', or that the world was not the same place. As I toured *BALL* more and more to theatres and medical schools, I began to be able to tell when someone asking a question was about to cry. Recognising that this had nothing

to do with me, but rather about the questioner and the illness being dealt with in their own life (either a loved one's or their own), I would brace for the story to be told. There was no question in their Q&A question. While I had both sympathy and empathy for these people without questions, my response grew to be similar after more and more people were (not) asking questions and welling up after sitting in a room where cancer had been talked about for an hour.

I instantly recognised the need for these questioners to give voice to their issue, to telling the story publicly, as after all, I was doing just that. Much like the 'performances' done by web commentators on the work of Rita Marcalo discussed in Chapter 2, the Q&A's here functioned as a live space for people to perform their own narratives. These narratives are, in some way, being shared in hopes of achieving completion — an answer — which I was unable to provide, first and foremost because the answer was not mine to give. Or, maybe, as I hint to above, these questions had little to do with me. The questioners at the Q&A may have been trying to create their own narrative and picking up on the opportunities a public sharing might provide. Tami Spry, who wrote about her performance *Skins: A Daughter's (Re)-construction of Cancer* (1994), wrote that creating and sharing a cancer narrative offered her the opportunity "to speak the personally political in public, [a process] which has been liberating and excruciating, but always in some way enabling".⁴⁰ For Stacey, the process of creating a narrative out of one's own experience is similarly enabling but differently inflected, with the narrative creating a therapeutic distances, writing:

Narrative offers a path out of the pain and a guarantee that it will not be forgotten. This may be the kind of remembering that heals. Restorative writing. But perhaps I am also writing to forget.

⁴⁰ Spry in Heddon, p. 27.

Narrative places experience firmly in the past. In the telling it is over. With others knowing, am I finally allowed to forget?⁴¹

While both Stacey and Spry speak to the desire for those with cancer to create and share narratives, they do not address why audiences seek out this work. While people may access work like Armstrong's for their interest in a true life story (similar to why they might watch *Brian's Song*), or a desire for catharsis (as might inspire people to access *Terms of Endearment* or *The Bucket List*), the high number of crying question-askers and copies of *It's Not About The Bike* appear, to me, as evidence that people access the work most distinctly because of their presumed relationship to the material. Cancer books are read by cancer patients; as Jackie Stacey writes about cancer books: "like so many other subcultures it [the cancer books] remains invisible until [it] becomes relevant and then, as if by magic, seem[s] suddenly all-pervasive."⁴² This is even true when considering those who write on topics of cancer — Spry, Stacey, Susan Sontag and myself, as just four examples — whose work is mired in an interest in health and bodies which was developed in and around their own experience with cancer. While most audiences attend work that they will have an inherent interest in, the strict linguistic and culturally constructed barriers intensify the division between those with cancer and those unaffected by cancer. If the isolating experience of illness mentioned above is so individually felt for cancer patients, then presumably, those with cancer may be more enthusiastic to find similar people, and connect with spaces and communities where they can feel less alone.

⁴¹ Stacey, p. 245.

⁴² Stacey, p. 2.

And yet, even though I understood and appreciated where the crying question askers were coming from, it began to feel boring or predictable after some time, not because the emotions weren't real, the tears weren't real or the pain wasn't real, but because the stories felt strikingly similar. This process of hearing story after story is captured succinctly by Petra Kupperts with the phrase 'compassion fatigue', used in relation to creating and sharing performance work about disability.⁴³ Kupperts writes about how this fatigue is experienced:

Listening to these accounts, my attention does wander, even though this is the heart blood of my chosen life—these are the people whose company I seek, with whom I feel comfortable, with whom I make art, with whom I make a life, to whom I disclose my own stories.⁴⁴

While some people could read Kupperts' or my own reactions as jaded, I suggest that it is only because the narratives of illness and 'coming out' about illness, to me at least, read as almost an entrance pass, or ticket to enter the real conversation about illness, bodied experience and otherness. It's not that the stories are not welcomed, but rather that they fail to tell more than basic introductory material, especially if the language used to introduce the illness is so similar as previously discussed. Although the straightforward language — that which is present in *The Bucket List*, *BALL*, *Exposed* or *Terms of Endearment* — feels like the most natural to the individual, it is as much as a learned response as our basic manners. Even about touch, Kupperts believes that this may not be proof of a unique individual connection, writing, "When someone's hand reaches out to touch someone who is upset, that gesture can feel ingrained and predictable".⁴⁵ Far from being bored with the person's

⁴³ Petra Kupperts, "your darkness also/rich and beyond fear": Community Performance, Somatic Poetics and the Vessels of Self and Other', *M/C Journal*, 12, 5, 2009.

⁴⁴ Kupperts, "your darkness...", 2009 (As this is an online journal, no page numbers are indicated).

⁴⁵ Kupperts, "your darkness...", 2009.

legitimate sorrow, finding myself bored with other's sorrow always stemmed from an actual desire to see past a simple, albeit emotional, description of an illness. As much as their welling up is their entrance into this conversation, perhaps *BALL* is my own. With *BALL*, I could get through the 'details' phase of my illness — tell everyone, all at once, how I was diagnosed, how it was to have chemotherapy, etc — and leave the more involved and personal issues to be discussed one-on-one or at a later date. This usage of the cancer story — like *BALL* — is elucidated by Arthur Frank in *The Wounded Storyteller*:

[...] the phone rings and people want to know what is happening to the ill person. Stories of the illness have to be told to medical workers, health bureaucrats, employers and work associates, family and friends. Whether ill people want to tell stories or not, illness calls for stories.⁴⁶

If the Q&A provides for audiences a chance to share, or even practice, these details or stories (especially if they have not previously) they may be hoping to get feedback (the answer) on their experience. Unfortunately — and more often than not — the cumulative effect of these stories (these non-questions) can be tiring.

Despite the compassion fatigue I thought I would feel towards Armstrong or the LIVESTRONG world, with its sharp marketing and unceasing promotion of Survivorship lingo, and the same resistance to being emotionally invested in cancer stories, I still cried while reading *It's Not About the Bike*. While much of the emotional impact traded in sports metaphors, which had little to relevance to me, I was struck by the similarities in our stories — and humbled to find some of the exact same language and description in our experience. There was first the literal similarities: Lance Armstrong and I were treated at the same facility in Indianapolis, with the same team of doctors and even the same walk from the

⁴⁶ Frank, p. 53.

hotel adjoining the medical centre to the cancer ward. It was a memorable walk through a covered bridge linking the two buildings over a major intersection. To read about this similar walk in Armstrong's memoir made me suddenly connected in a way that I hadn't thought would be possible. We have so little in common, but it was this very small detail, the cold bridge linking two relatively handsome buildings, which demonstrated that perhaps these narratives are not so different.⁴⁷ Perhaps, and shocking to my position as a queer man outside the heteronormative culture of sports, Lance Armstrong and I had common ground. There were clear differences: my experience with the sperm bank was filled with awkwardness (as I came out to my mother as queer the morning before my surgery) and my post-cancer triumphs were on a significantly less-public scale. Because I was in college at the time and still under my parents' health insurance (this was the US after all), I did not experience the same worries as Armstrong about financial security, but I had, during my illness, developed a political sensibility and firmer belief in universal access to healthcare.

More so than the details of place and space, I was struck by how similar our language was when describing cancer, diagnoses, hair loss and even the experience of being watched. Not only was the sentiment the same, but so was the actual wording, even the same syntax. Nearly eight years after writing *BALL*, and writing that I found myself "dropped in a foreign country where I didn't speak the language — cancer", it felt eerie to read about how Lance Armstrong "mastered a new language, [with] terms like ifosfamide [one of my cancer drugs too], seminoma [my specific kind of tumour as well] and lactate dehydrogenase (LDH, another blood marker) [a number which also told me

⁴⁷ Lance Armstrong, *It's Not About the Bike* (London: Yellow Jersey Press, 2001), p. 106.

whether or not I still had cancer]”.⁴⁸ I found myself calling my parents to confirm that, while I had cancer and was loopy from drugs and surgery, I had not actually read the work; sometimes the words seemed so similar. There was something about the use of the cliché (describing a cancer diagnoses as the ‘tip of the iceberg’ which caused people not to know ‘which way was up’, for example), which, as much as I wished to deny it, connected what I had written to Lance Armstrong, and to Annie Sprinkle/Beth Stephens, and to many of the movies which had come before. I find *BALL* littered with clichés, much to my own writerly dismay. The presence and similar employment of such cliché made me feel like I had, while high on morphine or oxycontin, read and absorbed *It’s Not About the Bike*, but may more presciently speak to the banality of language or policing of conversation about cancer. While Ebert recognises a cancer diagnosis as promoting the end of one’s usage of ‘sitcom clichés’, I argue that the discussion of cancer has been so policed — both by films and standardised medical procedure, or training like with OSCE examinations — that the cliché is a learned behaviour, with a language and grammar all its own. Ever since ‘Jimmy’ was greeted by the Atlanta Braves baseball team and sang ‘Take Me Out to the Ballgame’, cancer patients have understood how this illness would be discussed, fundraised and treated. As much as cliché felt the bane of my writerly existence — and something I struggled with throughout the writing of this thesis — perhaps this struggle exemplifies an important aspect of the cancer experience in contemporary discourse.

⁴⁸ Armstrong, p. 92.

Copping Feels in Real Time: Reading Cancer Blogs

By the time I'd discovered the blog of Kris Hallenga, her blog *Kancer and Kris* had already been transformed into Coppafeel.org, a glossy, well-funded, national UK campaign promoting breast cancer awareness for women under 50, encouraging them to insist on referrals and for them to be recognised as an at-risk population.⁴⁹ Reading Hallenga's story on Coppafeel's website is harrowing: she was diagnosed six months after noticing a problem, only after being turned away twice by doctors who were convinced that the lumps in her breasts were a natural result of hormones. The new site contains limited reference to the blog Hallenga wrote, starting in 2009, which started her entire campaign. Through some searching of the Coppafeel site, it is possible to find the original blog — www.kriskancer.squarespace.com — a simple site, held by an open-source server, which still contains the original writing.

Hallenga's blog starts soon after her diagnosis, but the writing, much like *Music is Disease*, begins by telling us why the audience is here, and why the blog has been written. Although the blog is close to being in real time, some things are already in the past — descriptions of months of unexplained symptoms, lumpy breasts and worried conversations with her mother — all of which have only made sense in retrospect, similar to how Stacey described her cancer experience. This narrative back-then-forth is not exclusive to cancer stories, but I will demonstrate how it becomes particularly meaningful when reading real-time cancer narratives such as the cancer blog. As Mark Currie writes in *About Time*:

The present for a reader in a fictional narrative is not really the present at all but the past. It is somebody else's present related to us in the past tense. Though it seems like the present, because it is new to us, it is tensed as the past, in what the French call the

⁴⁹ 'Coppafeel Homepage', *Coppafeel*, <www.coppafeel.org> [accessed 16 November 2010].

preterite, a tense otherwise known as the past perfect or the past historic. We are narrated to in the preterite, but we experience the past tense in the present. But because it is the past tense we know that there is a future present, in relation to which the present of the narrative is past.⁵⁰

While Currie discusses time in relation to fictional narrative, the experience of discovering a non-fiction narrative is similar in this regard. As readers, he argues, even if the book is set in the present moment, we are well-aware that it is in the past — the words have been conceived and written by someone else, and that a real-time account would be almost anathema to the medium. The overall result of this play with present, past and future generally rarely affects a work's reception, as the form takes such play as given, thereby making the blog a potent intervention into an understanding of time.

Much live art and interventionist performance attempts to interrupt the play of time presented in novels — or even theatre based on a previously written or devised script — by highlighting that the presented, or performed world of the work, is in the present and shows us access to a world that is now, now. This play between different understandings of time is described by Schneider as demonstrating the *theatricality* of time, in which “time plays forward and backward and sideways...”⁵¹ Gob Squad's performances, sitting somewhere between theatre and live art, such as *SuperNightShot* (2002) or *Revolution Now* (2010) present reflections on time and the way we experience narrative in performance. *SuperNightShot*, for example, features the Berlin-based ensemble taking live feed on four video cameras for one hour prior to the stated performance time. When the performance begins (it has been shown in a

⁵⁰ Mark Currie, *About Time: Narrative, Fiction and the Philosophy of Time* (Edinburgh: Edinburgh University Press, 2007), p. 5.

⁵¹ Rebecca Schneider, *Performance Remains: Art and War in Times of Theatrical Reenactment* (New York and London: Routledge, 2011), p. 6.

number of different cities but was, most famously, in Berlin), audience members are asked to cheer and welcome home their heroes (the ensemble), who enter extravagantly, instantly rewind the videos they have just taken and show all four unedited feeds. The four unedited feeds had started one hour prior, include separate and elaborate journeys by the four ensemble members throughout Berlin, and end with the what the audience experienced as the beginning.⁵² Although an audience can be aware that the piece has been devised in the past, the unedited live feed highlights that the ‘performed’ work was created in the immediate past, doing away with questions about a script or text’s history and whether or not the audience is experiencing the past, the past perfect, or the future present, as it is a combination of all three. This playing with past, present and future disrupts the traditional representations of time and may be useful in understanding how cancer blogs combine different time periods and shake people outside of the routine whereby they recognise the expectant chronology and time period associated with a cancer story.

Cancer blogs disrupt the traditional representations of time, mostly because they start as a present-tense blog entry which is dated, timed, instantly accessible and usually starting with a phrase such as ‘I’m starting this blog...’ We can almost get it in real time. The Cancer Blog is dependent on the backstory such as ‘This is why we’re here/We’re here because a few weeks ago I was diagnosed with so and so’. For example, Hallenga’s blog begins by addressing these months of unknown symptoms similar to Nicholls’ *Music is Disease* which says “I was feeling weird, so I went to the doctor...”. Nicholls and Hallenga start in the present but need first to provide the prologue. Although Nicholls and Hallenga do an exceptionally thorough job of describing what

⁵² ‘Super Night Shot’, *Gob Squad*, <http://www.gobsquad.com/currentsubpage.php?id_project=4> [accessed 3 January 2011].

came before, the introduction to what will be real-time blog posts (or as close to real-time as the mechanics of blog postings allow) feels a very common trope. The cancer-as-blog-starting-impetus is in fact so ubiquitous that it is captured in major cancer campaigns including Real Time Cancer. Real Time Cancer (founded in Canada and, in 2008, was incorporated as a subset of Young Adult Cancer Canada) was based on the principle that young adults will turn to the outlet of blogs both to express their thoughts instantly and also to read thoughts of others, creating a 'real time' community that was responsive and healing.⁵³

Once readers are caught up to the present, they can quickly follow Hallenga's story, which includes chemotherapy, an interest in herbal remedies and hairloss (which is accompanied by pictures). While I was not surprised by the aesthetics or energy presented by Coppafeel's site, I was quite taken aback by Hallenga's already-positive attitude in her first blog post, on 19 February 2009:

19th February....on this day in 2001 a huge case of foot and mouth disease was found at a UK abatoir...on this day in 1997 China's reformist Deng Xiaoping dies..on this day in 1985 Eastenders was first broadcast on British TV... on this day in 2009 I was diagnosed with breast kancer... It is impossible to describe that second of immense fear and disbelief when the doctor tells you the news. A tiny part of me had already sensed something was a little bit wrong... But still, not in a million years did I expect THIS. That lumpy boob that had given me grief for a year had festered into this evil mutant disease that would change my life forever.⁵⁴

Hallenga seems an impassioned voice from the beginning. Her tone suggests that she has started her blog to make public the fight and, immediately following this, to educate people around the dangers of breast cancer for young adults.

⁵³ 'Young Adult Cancer Canada Homepage', *Young Adult Cancer Canada*, <www.youngadultcancer.ca> [accessed 16 November 2010].

⁵⁴ Kris Hallenga, *Kancer & Kris: kristin's guide to gardening — nippin kancer in the bud*, 19 Feburary 2009, <<http://kriskancer.squarespace.com/>> [accessed 11 November 2010]. Spelling is purposefully left uncorrected here.

Her scope is wide, connecting to world history, and speaks to a general readership, which is probably a mix of friends, family and interested fellow bloggers. As Frank writes about cancer patients for whom the illness begins a 'quest', Hallenga seems to fit his definition well as an example of a person who does "not want to go back to a former state of health, which is often viewed as a naive illusion. They want to use suffering to move others forward with them."⁵⁵ Within months of beginning her blog, Hallenga's campaign jumps in scale. She writes in her blog, "My new campaign is coming along very nicely all thanks to some wicked people helping me out [...] I can't give much away as it will be launched in one big ass blow out for maximum exposure and effect",⁵⁶ and this seems to be the spark of the Coppafeel organisation. With this quote, the blog motions to something that happens inside blog culture and something that affects the cancer blog narrative: there is another world going on outside the blog to which the reader is not privy. In moments like this, the author motions to a life outside the blog, which in turn distances the reader from the experience.

Music is Disease features a motioning to life outside the blog in a manner similar to Hallenga's blog, even though Nicholls' blog was much more frequently updated. At the very beginning of his blog, Nicholls talks about being single on Valentine's Day, describing himself as a "lonely whacko". While he mentions many friends throughout the blog, it is not until May that he begins writing about his boyfriend Chris, who suddenly takes centre stage as Paul's main support and caregiver. As a reader, I found myself cheered by this information that sneaked up on us — there was never a mention of dates, or how they met, or anything of the sort, but suddenly, they were together, and important to each

⁵⁵ Frank, p. 121.

⁵⁶ Hallenga, 11 May 2009.

other. “I now am very happy to stay in Glasgow”, he writes. “I have my boyfriend Chris which I have waited all my life for here”.⁵⁷ And with this, readers are exposed to an additional intimate side of Paul. While the blog had been seemingly intimate before, this new information shares even more of his ‘personal life’, in a way that consolidates the handful of times Nicholls had dropped Chris’ name previously in the blog. Much like Hallenga’s diagnosis giving meaning to isolated physical symptoms, the mention of Nicholls’ boyfriend seemingly brought together what had been previously individually insignificant parts. These entries by both Hallenga and Nicholls demonstrate how the real-time experience of a blog and following a blogger’s life are highly selective, like all narratives, and reminds the reader that these narratives are being crafted. Although the crafting of a blog might be less consciously manipulative than a reality television show like *The Real World* or *Big Brother*, these moments of breakage — of reference to something outside the frame — remind readers that this real-time is selective real-time (and not quite real time given delays in writing, posting and, presumably, reading).

While what happens outside the frame of *Kancer and Kris* eventually becomes the entire campaign — Hellenga blogs much less frequently about illness as she is no longer in active treatment and focuses more on fund- and awareness-raising — for Rosie Kilburn, business and blogging remain connected. Kilburn, diagnosed with hepatocellular fibrolamellar carcinoma — a rare liver cancer — in February 2009, began her blog *The Knock on Effect* in late March with the already-established intent of using the blog to tell her story and to raise money for cancer charities by selling t-shirts and other objects that promote discussion of cancer. Although no cancer charity is originally

⁵⁷ Nicholls, 30 June 2010.

announced as the recipient for the money in the blogs (perhaps demonstrating the connection that cancer = fundraising in its most general manner) Kilburn, at 18, has an optimistic outlook and speaks about cancer in its broadest terms. Because Kilburn's cancer is rare, much like Nicholls' (in that bowel cancer is very rare for people at age 26), the 'awareness' raised is about how young people can be affected by illness, how young people are not invincible and, perhaps, how young people need be vigilant about their health. This in contrast to Hallenga's, whose very clear message — CoppaFeel — is in the organisation's name. For Kilburn, blogging about cancer, family, school, work, and her business seem to fit nicely together and this may be in relation to the kind of cancer and treatment course she is experiencing. Kilburn's experience with cancer will not be a discreet event — a time out from her 'normal life' — it's a long treatment course with many aspects, including potential liver transplantation and various rounds of chemotherapy. For Kilburn, the taboo around cancer is the target:

[The t-shirts we sell] will be taboo, controversial and insane. Promoting that we can do it, we can survive; because we want to. It will stop people skirting around cancer as if it's a swear word and start to make them talk! I've found that whilst I have been surviving cancer a lot of the people around me have become scared to talk to me because of the barrier that cancer creates — That is what I want to change; it's okay to talk about it..It's okay to talk to me.⁵⁸

Written in March 2009, one month after her diagnosis with cancer, Kilburn's focus on the silence around cancer demonstrates how keenly such an aspect seems to be experienced after a diagnosis. Simultaneously, however, it feels important to consider the scope of such a silence. How severe is the silence, experienced by Kilburn in the month after diagnosis, that it led her to start a

⁵⁸ Rosie Kilburn, *The Knock-On Effect*, <<http://theknockoneffect.wordpress.com/what-im-doing-here/>> [accessed 10 November 2010].

fundraising campaign about breaking silence around the C word? If she felt a desire to be silent — as has been explored in Chapter 1 — this is very different than her being on the receiving end of silence, as if people around her were policing the language which could be spoken. I often felt like I was on the receiving end of silence after being diagnosed with cancer — or as Frank describes, an utterly monadic body which understands itself as existentially separate and alone.⁵⁹ And yet, I wonder if the ‘experiencing a world of silence around cancer’ might be as socially constructed an expectation of cancer than everything else. Both Kilburn and myself felt such a silence, and intensely, and yet we live in the times of Lance Armstrong, large-scale MacMillan advertisement campaigns and high cancer survival rates. This is not to say that people do not remain uncomfortable engaging with conversations about illness and mortality, but rather to say that perhaps the feeling of isolation may be as learned a trait as any, or a remnant of the communication present in *Terms of Endearment* or *Brian’s Song*, where the C word was rarely mentioned.

This silence experienced by those with cancer may be altered by a consideration of Garland-Thomson’s stare, a feeling of being watched, judged and policed, which the staree can have some power in controlling. By viewing the silence experienced (and commented on) by many, the stare/staree relationship may be addressed by the cancer blog in a manner not previously possible. In response to the silence that Kilburn writes about experiencing, her blog uses its own technology to address (and hear back from) its audience. Although all blogs feature areas for comments (typically at the bottom of each entry), Kilburn, Nicholls and Hallenga engage with the comment board in a unique way by prompting the comments they wish to hear. Comments range from Kilburn’s

⁵⁹ Frank, p. 36.

open comments “So yah, comment if you want pics of my new mohican :)” to the more targeted “Gimme some jokes, we all like to laugh!” which give audiences/readers a clear understanding of what is being asked of them.⁶⁰ *Music is Disease* does the same, with Paul asking seeming-inane questions at the end of each blog entry such as “cheese n onion or salt n vinager?” or “wonderbra or wonderwoman??”⁶¹ Although flippant in tone, both of these examples demonstrate an attempt by the producer of the blog/work to receive clear responses from their audience. As blogger Margaret Mason writes in her book *No One Cares What You Had for Lunch*, the asking of questions and collecting of interested people allows audiences/readers to “Let us cheer you on” which not only satisfies the writer, but engages the reader and leads to a higher number of visitors to a blog.⁶² Perhaps they are wanting something light, or wanting something more serious — people asked everything from how Kilburn’s campaign is going to more intimate information like asking to see pictures of her hair cut — but the blog provides an opportunity for blogger and audience to connect in a manner which derives from a blogger’s need. If the blogger, in this case, is a cancer patient who has commented on isolation and silence, the blog serves as a method to undo this circumstance, or at least to make a start.

The significance of the questions presented on a blog may address the rationale for why people read cancer blogs in the first place. Because the first people to read a cancer blog — as evidenced from comments on Hallenga and Nicholls’ initial blog posts — are those intimately connected with the blogger/

⁶⁰ Kilburn, 11 April 2009 and 19 May 2009.

⁶¹ Nicholls, 12 February 2010 and 15 February 2010.

⁶² Margaret Mason, *No One Cares What You Had for Lunch: 100 Ideas for Your Blog* (Berkeley: Peachpit Press, 2007), p. 84.

patient, the blog may demonstrate an almost Levinasian response to issues of alterity. As Helena Grehan writes about Levinas, his “theory of alterity claims that when the other [in this case, a cancer patient] calls us we have no option but to respond”.⁶³ Because cancer diagnoses, as previously discussed, create a reorientation between individual patients and their experience of the world, very quickly those people experience being the other, one who is prodded, poked, protected and scrutinised by others. Levinas’ claim that subjects (those without cancer in this case) have no choice but to respond may rationalise the invention of website like LotsaHelpingHands which help family and support systems to organise meals for patients and separate out the work of cancer care. Blogs in this way, provide a way for audiences to *do* something for the other, and reject the more traditional narratives which focus on catharsis or celebration, two emotions which assist the audience much more than they do the patient.

The questions asked of a blog’s reader, however, are not always direct like the postings on LotsaHelpingHand, nor are they always humorous or translated to audiences in a light-hearted way. As Nicholls’ blog continues over six months, the concluding questions often resonated for me as a reader. “Staring into Space or going into Space?”, “If you wouldn’t let a dog suffer why a human?”⁶⁴ The questions seem so innocent, so related to the convention of asking questions on a blog in order to receive an answer, and yet, the questions resound deeply and provide an insight into the mind of a cancer patient. This insight gained by “If you wouldn’t let a dog suffer why a human?” is, I try to remind myself while reading, not necessarily different than the insight provided

⁶³ Helena Grehan, *Performance, Ethics and Spectatorship in a Global Age* (Basingstoke: Palgrave Macmillan, 2009), p. 6.

⁶⁴ Nicholls, 1 May 2010 and 15 May 2010.

by “cheese n onion or salt n vinegar?”; together they build a picture of a full life built with illness, in which the profound mixes with the mundane. During an illness, the moments of saying goodbye or hearing bad news often happen at the same time as vomiting or as comas. While *Terms of Endearment* presents Emma, in one of its final scenes, steeling herself for a quiet and emotional farewell to her young son where she attempts to look healthy, not all courses of illness allow for this cleanliness or quiet. It is precisely this lack of differentiation that, to me, makes Nicholls’s final closing question “Egg and chips or full fry up?” ring with such poignancy.⁶⁵ Different from the essential life lessons of perseverance and a ‘positive outlook’, as are demonstrated in *It’s Not About the Bike* or *BALL, Music is Disease* ends without knowing that Paul’s life would end before another entry would be written. It’s innocent, life affirming and yet completely innocuous. The power of the concluding statement, to me, results from the live moment in which it was written and the real-time transmission of the blog to its readers.

The cancer blog allows audiences to become engaged in an individual’s story about cancer without the author predetermining how that story should be read, i.e., if it should be read with a pitiable tone or a cheerful and positive outlook. The blog allows the individual creator to write exactly how they feel they should, without the pressures of an audience already knowing whether they live or die. This is not to say that other cancer narratives cannot be free from predetermination, or capable of expanding the definitions of survivorship stories or bereavement stories, but the blog, with its nature as a story which unfolds in real time (or gives the impression of unfolding in real time), provides insight into the intimate connection between a person with illness and those

⁶⁵ Nicholls, 3 August 2010.

who are witnessing that illness, be they family members, immediate friends or remote individuals who are accessing their blog because of a feature in *The Guardian*. Cancer blogs, because of all the above, may demonstrate a relationships that is both highly mediated — as in, using a computer screen as a mediating factor between two people — and a relationship between a performer, or object for observation, and the audience, that is unmediated — as in unencumbered by the history of cancer survivorship or bereavement trajectories as complicated cultural signifiers. From the perspective of the blogger, maintaining the blog can function as a way control and respond to the stare that they may be experience, and to create a narrative away from their scattered or traumatising experience of diagnosis and treatment. It can allow them to educate their peers, or to pass information quickly to a large number of people instead of having to repeat either good or difficult news over and over again. Finally, maintaining a blog can also function in finding a witness, or even a community of witnesses for their story which, because of the individuality of embodied experience or a learned history around cancer, may make them feel incredibly isolated.

Memorial Settings

In 2010, significant debates happened around Facebook and the privacy — or lack thereof — of its users (account holders) when it was revealed that Facebook had been allowing an outside computer programme to scan people's Walls, status updates and messages, matching scanned words for personalised and targeted advertisements.⁶⁶ Although I found myself mostly neutral about

⁶⁶ Nick Bilton, 'The Price of Facebook Privacy? Start Clicking', *The New York Times*, 12 May 2010, <<http://www.nytimes.com/2010/05/13/technology/personaltech/13basics.html>> [accessed 26 December 2011].

these debate, my interest in Facebook privacy settings piqued when related to Users who have passed away. When a person who holds a Facebook account dies, and has their death reported to Facebook (via confirmed obituary or the like) the account goes into Memorial Setting which allows the deceased's privacy to be better kept. "Memorialising an account", Facebook writes

removes certain sensitive information (e.g., status updates and contact information) and sets privacy so that only confirmed friends can see the profile or locate it in search. The Wall remains so that friends and family can leave posts in remembrance.⁶⁷

Following Grant's death in February 2010, I remember vociferous, emotional conversations among my group of friends about how we could restore his Facebook settings. We wanted access to his old status updates and such "sensitive" information, but the monolith of Facebook was unshakeable, and eventually we acquiesced to their standards. We just continued to hope that the account would not, one day, be deleted.

Because I saw myself as a fan of Paul's writing — both personally and professionally as a research subject — I so yearned to see that Facebook Wall, with the memorials by good friends and never-before-posted pictures which were perhaps too embarrassing to show during his lifetime or which never felt urgently necessary to post. The blog had been public, but his Facebook Wall, that was for the people he knew and loved. Suddenly I felt sad, distant, denied the privilege of something which I thought, as a discreet but enthusiastic follower of his blog, I had earned.

And one day, it opened. His Facebook Wall was suddenly public, for all to see. The blog — his creation — could not live on, but with an online memorial, now that it was managed by others, it was possible for Paul to be included in

⁶⁷ 'What does memorialising an account mean?', *Facebook FAQ*, <<http://www.facebook.com/help/?page=842>> [accessed 11 November 2010].

the lives of those who were survived by him, similarly to how Grant's Wall has become a living memorial which continues to be added to weekly by various friends. If cancer blogs function to allow cancer patients to narrate their experience unencumbered with the cultural heaviness surrounding ordinary cancer stories, perhaps the online memorial is the ultimate form of audience response. Having taken in the narrative, as idiosyncratically presented by one individual, the Facebook or similar memorial allows an audience response which cannot be responded to, acted upon, or expected by its creator. Only now does it become the audience's opportunity to control the tone and content of the conversation. While the Memorilised Accounts contain regulations governing the posting of phrases, links and pictures in these spaces, and the people who are permitted to post to them, the online memorial may serve as a form of rousing audience applause. The performance is over, and now it is the audience's turn to clap, to cheer, and to demonstrate their appreciation of the work that has made, in many cases, with themselves in mind. While an actor or singer usually bows in this moment of applause, the absence of the performer, in this case, makes the applause all the more noteworthy. Although the audience might look around and soon enough wonder what or who it was that made them all stand and think and cheer and cry, they can look around the auditorium and find that they are standing with others, and not wanting to quiet down any time soon.

Chapter 4

Picturing Your Life: Practice-Based Research and the Affect of Cancer

Picture Your Life After Cancer

In April 2010, *The New York Times* published a feature entitled ‘Picture Your Life After Cancer’, a user-generated photo essay collecting stories and images from cancer survivors. “For the estimated 12 million cancer survivors in the United States”, the feature begins, “some of life’s biggest challenges begin after the treatment ends”.¹ Although the description recognises some of the potentially-difficult consequences of illness — “the disease or side effects of treatment can trigger physical changes” — its focus is clearly centred on positive outcomes, asserting that, “the cancer experience can lead to a shift in priorities, bring new insights or work as a catalyst to quit a job or try something new”. And most of the photographs deliver accordingly, with images of the Eiffel Tower, snow peaked mountains or cycling races dominating the landscape.

Photographs of cancer-as-positive-catalyst-for-change should not be a surprise considering the placement of ‘Picture Your Life’ in the *Well* section of *The New York Times* or because the submissions specifically asked for contributions of text AND photographs. As discussed in Chapter 1 (with regards to the work of Susan Sontag and Jo Spence), photographs are more common around celebration and accomplishments in relation to cancer than they are of private battles or some of the very real, but perhaps un-photographable side effects of cancer, such as bankruptcy, drug dependency or sexual difficulties.

¹ Karen Barrow and Tom Jackson, ‘Picture Your Life After Cancer’, *The New York Times Online*, 8 April 2010, <<http://www.nytimes.com/interactive/2010/04/08/health/cancer-survivor-photos.html?ref=health>> [accessed 3 March 2011].

These aspects of a life lived post-cancer are less likely to be momentarily paused for someone to say “Cheese!”

Out of the frame of the photo essay, however, readers are able to submit comments as with any online blog feature on *The New York Times Online*. These comments seem particularly devoted to individuals promoting their cancer blogs or expanding on the information in their photo submission. Individuals who contribute responses in this area also include bereaved partners who seemingly felt compelled to write about their experience but maybe did not feel comfortable submitting a picture of the deceased or felt as though the ‘Picture Your Life After Cancer’ structure precluded their participation.

Inside these margins — and perhaps it is telling that this exists inside the margins — a singular voice appears and challenges the presumptions of ‘Picture Your Life’ in a striking manner. In the most pithy response to the article, a woman identifying herself only as Claire writes, “Cancer ruined my fertility [sic] and my sex life. I was 26 when diagnosed. Life sucks now. Not what you were looking for?”² Claire’s sentence rips through the photo essay and the inherently happy-survivor focus of its set-up. The statement draws attention to the un-photographable nature of her personal experience and alerts a reader to ask what a photograph of infertility or a ruined sex life looks like? And if one were taken, would *The New York Times* allow such a photograph to be published?³ Claire’s statement also alerts a reader to the cultural assumptions that are made by the feature not only asking about the photograph-ability of a

² Tara Parker-Pop, ‘Picture Your Life After Cancer’, *The New York Times Online*, <<http://well.blogs.nytimes.com/2010/04/08/picture-your-life-after-cancer/>> [accessed 3 March 2011].

³ Claire’s comment is allowed on the blog section of *Picture Your Life*, though this seems to be a mostly-unmoderated part of the forum. This is different than with the picture/description uploading, a form had to be filled in and submitted, presumably for approvals before being uploaded into the montage of photographs.

post-cancer experience, but about whether people post-cancer would be interested in submitting photographs of their real experience (an experience such as Claire's) to a collage featured under the heading *Well*.

Claire's question is rhetorical, of course, based on her knowledge of how cancer is discussed and a positive message around cancer policed. Although her question presumed an individual experience, Claire's singular voice is suddenly joined by a small chorus of commentators who use her as a springboard for sharing their story. A woman identifying herself as Adria writes:

I agree with Claire... I was 30 when diagnosed and just 7 months out from a kidney transplant. I am 33 now. I have not dated since then, nor have I had a period. I have had sex twice and it was dry and unpleasant. Things are getting a bit better. But cancer before you have a family and a partner or some kids to grieve over you is just bad. No touching story in that.

And a woman known only as Indian Girl writes:

I completely agree with Claire.. I was diagnosed whn I was 23years.. had a Bone Marrow transpalnt and at the age of 23 itself I had to undergo menopause. So I am a cnacer survivor.. but wht do i celebrate the fact i can't have kids. Now i am 31yr old have to be on medication life long. have to show to my doc every 3mths and answer questions why i am not married coz physically i lok so healthy.. I hate facebook coz all the time i am reminded i m the one who is incomplete as all my contacts are haveing babies.. its a baby boom!!⁴

The most striking feature of the above (beside the evidence of a deeply engrained cultural assumption that procreation = fulfilment) is that, unlike other statements in the Comment section, all of these comments build off of Claire's example. Nowhere else in *Picture Your Life After Cancer* do commentators refer to other commentators — most are seemingly just interested in sharing their own stories that were not able to be edited into 150 words. From their comments, it can be inferred that Adria and Indian Girl both read previous

⁴ To most effectively capture the experience of reading these blog posts, I have again left original spellings here.

comments in hopes of finding a voice that, even in some way, spoke for their own experience, hence the reference to Claire. Inside these comments, Claire's four sentences are responsible for the starting of a second, separate narrative as much about fertility and sex as it is about survivorship and policed, positive language. Claire's comments, in their frankness, challenge the presumption made by the entire project, namely that people's experience with cancer has brought some kind of positive change. The responses to Claire — and particularly the fact that they responded to her by name — evidence that her statement was read by those who were searching for a voice which matched their own. Upon finding this opinion, these contributors found a context for their experience and added their agreement, thus strengthening the case that Claire had made. Although before reading Claire's statement Indian Girl and Adria may have felt alienated from the article/photo essay, Claire's simple comment may have opened up an avenue for their participation.

One voice farther down in the blog, from JoAnn Holloway, attempts to incorporate Claire's experience into the narrative of the project itself, saying "Claire's experience with cancer is just as valid as the myriad of uplifting stories attached to the pictures" and "I hope she posts a picture..." but most voices ignore Claire completely. The exception to the silence around Claire's comment is by Lori Hope, author of the book *Help Me Live: 20 Things People With Cancer Want You To Know*, who responds thoughtfully in the same comment section:

I so appreciate your comments. Although life changes for the better for many of us – or we can at least try to find some "silver lining" or look on the bright side so we can keep on going day to day – cancer sucks, big time.

Lori Hope, however, ends her comment by reaffirming the process and the project, writing:

That said, many of us do eventually come to see our cancer as, if not a gift, at least an impetus for change. Or a reason to write a book or make a film or look up an old friend. For now, I just hope you feel free to express your anger, grief, and pain, and feel heard. I am holding you in my heart.

Whether Claire wishes to be held in Lori Hope's heart or not is never answered in the Comment section under 'Picture Your Life', but it is clear that the formula presented by 'Picture Your Life' is one comfortable for many thinking and working inside the industries which support and treat people with cancer.

Ehrenreich, discussed in Chapter 2, rails against such 'gift' talk, describing such an expression as an "extreme characterisation".⁵ If it does nothing else, 'Picture Your Life' may be yet another example of cancer work which, as Stacey writes, views "cancer as an opportunity for salvation" and with which many people (myself included) have taken issue.⁶ Preferring a Levinasian approach, I find myself with Ehrenreich and Stacey, clearly aligning ourselves with his writing in 'Useless Suffering' which says that "the least one can say about suffering is that in its own phenomenality, intrinsically, it is useless, 'for nothing'", perhaps to the dismay of people like Lori Hope and the authors of 'Picture Your Life'.⁷

The formulaic nature of 'Picture Your Life After Cancer' prompts a certain type of response from its readership, tapping into the cult of positivity (discussed in Chapter 2) and not necessarily making space for other types of engagement with illness or alternative tones around cancer treatment or survivorship. Nor does it allow space for cancer non-survivorship. By asking "How did your life change after cancer?" the narrative becomes exclusively

⁵ Barbara Ehrenreich, *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America* (New York: Metropolitan Books, 2009), p. 29.

⁶ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (London and New York: Routledge, 1997), p. 1.

⁷ Levinas, Emmanuel, 'Useless Suffering,' trans. Richard A. Cohen, *The Provocation of Levinas: Rethinking the Other*, Robert Bernasconi and David Wood eds. (London: Routledge, 1988), p. 157.

about cancer survivorship, without creating space for those whose cancers went ‘unsurvived’, nor does it necessarily encourage caretakers or bereaved families — who may be reading because of the subject matter — to submit photographs as some of the examples in the Comments section demonstrate. The prompt for submissions states “Space is limited to 150 words, so please pick one compelling story that best describes your post-cancer experience.” 150 words — the length of this paragraph — is all that is available to describe a person’s entire post-cancer experience. Which piece shall they choose?

Although word limits are, by their nature, restrictive, the prompt to tell a compelling, illustrative story in a short span of time seems a perfect metaphor for how stories about illness are told, beginning, middle and end, with a clear trajectory towards either survivorship or death, and without non-essential information or significant divergences. It is less the pressure to be quick about it, and more the pressure to be all-inclusive about it. This way we know the conclusion, be it happy or sad. And if it’s all-inclusive, then we don’t have to talk about it again. It was this pressure that led me to create *Other Funny Stories About Cancer* in 2006, and it was a continuation of this thinking that informed *BALL & Other Funny Stories About Cancer* in 2011, a bringing together of my three “cancer” performances (*BALL*, *Other Funny Stories* and *An Appreciation*) created over 10 years. *BALL & Other Funny Stories About Cancer*, which presents slightly-edited versions of all three pieces one after another in a 75-minute performance, demonstrates that illness is not a discreet event which can be written about in a singular moment, put away and never discussed again. ‘You’re still talking about your cancer?’ I can imagine people saying... Yes, yes I am. The putting together of the work is a political act for me and recognises the shifting meanings of illness over time, from a medical reality to a lens through

which to see the world both socially and politically. This is particularly evident by having *BALL* — with all of its expressions of bodily discomfort — side by side with *An Appreciation* — which starts with members of the audience touching my genitals — without describing the journey between the two, other than by saying that the former was written in 2003 and the latter in 2009.

The main goal of my performance work has been to create alternative narratives around illness that promote reflection on how cancer is discussed, framed and read by audiences. In this chapter, I will examine my practice-based project *Fun with Cancer Patients*, funded as a Research and Development Arts Project by the Wellcome Trust, and demonstrate the strategies the project took to challenge all-inclusive narratives of an individual's cancer experience. I will also question the usefulness of narratives themselves when considering illness or marginalised experience, such as disability, which have such heavily-coded cultural signifiers demanding certain readings. I will also examine the *Fun with Cancer Patients Canvas* function — an interactive picture-making tool on the *Fun with Cancer Patients Website* — which encouraged remote viewers to think critically about the imagery associated with cancer, and to play with such imagery in unexpected and perhaps transformative ways. I hope to demonstrate that *Fun with Cancer Patients* gave voice to people who, like Claire, found the tools established for cancer patients to be limited and reaffirming of the policed positivity that has already been discussed. Although *Fun with Cancer Patients* does not presume to fix all problems associated with photo montages like *Picturing Your Life After Cancer*, I will argue that *Fun with Cancer Patients* opens up new spaces for expression and works to capture a truly patient-focused experience inside of performance creation and reception.

Eat Me: Research, Development and Canvases

Although I am not sure if I read Petra Kuppers' *Bodies on Edge* before or after creating *Fun with Cancer Patients*, her final chapter on her practice-based research project *Traces* (2000) is a key context for my research when contextualising *Fun with Cancer Patients* into my research.⁸ Additionally, her extraordinarily helpful *Community Performance: An Introduction* highlights and references most of the major ethical and processual issues inherent in working in the realm of applied/community performance, and it is through these two works that I will frame much of my analysis and discussion of *Fun with Cancer Patients*. Kuppers understands community performance "to be work that facilitates creative expression of a diverse group of people, for aims of self expression and political change".⁹

The second theorist that I will consider as crucial for my written consideration of *Fun with Cancer Patients* is James Thompson, whose work in *Performance Affects* thoughtfully demonstrates how applied or community-based projects can and must be in dialogue with the world outside the performance- or action-making group. Thompson's work differs from Kuppers' approach in that his work highlights "the problematic relationship between applied theatre's relative invisibility and demands for a public articulation of purpose", while Kuppers' work prioritises the performance-making group or participants and, almost exclusively, their personal growth.¹⁰ This is not to claim

⁸ Petra Kuppers, *Disability and Contemporary Performance: Bodies on Edge* (London and New York: Routledge, 2003).

⁹ Petra Kuppers, *Community Performance: An Introduction* (London and New York: Routledge, 2007), p. 3.

¹⁰ James Thompson, *Performance Affects: Applied Theatre and the End of Effect* (Basingstoke: Palgrave Macmillan, 2009), p. 9.

that Thompson's work takes a cavalier approach to his participants' emotional or physical safety (in fact, very much the opposite), but rather that the written iteration of the research is consistently engaged with "how the work is refigured, co-opted or put in the service of diverse public discourse".¹¹ His research, therefore, measures the intimacy and necessity of the group's comfort while in continual dialogue with outside discourses. My engagement with this outside discourse was crucial for me, both because my aim was to create an applied practice which could respect the needs of patient participants while simultaneously speaking to a broader public, and also because the Wellcome Trust — who funded the project — as part of its Arts Awards remit, does not fund projects which it deems to have a direct therapeutic outcome as their goal. While the latter statement makes many unnecessary assumptions about how a piece of work or process could be perceived as therapeutic, it was the initial goal — creating an applied practice which could respect the needs of participants while simultaneously speaking to a broader public — that was my more central goal. In this chapter, I will demonstrate the complex relationship between such a definition of community or applied performance, the remit of the Wellcome Trust and my own desires as a performance practitioner and former cancer patient. While I believe firmly that my project facilitated creative expression for the patient participants and had a strong imperative for a change in attitudes, the role of self expression and political change varied greatly in different moments of the process and for the project's various audiences which I'll discuss here.

Although Kuppers' project *Traces and Fun with Cancer Patients* were quite different in their focus, output and methodologies, they were similarly

¹¹ Thompson, p. 34.

responding to, as Kupperts describes, the “limited ranges of images” that are available to the general public, in the case of *Traces* about mental illness, and in the case of *Fun with Cancer Patients* about, as the name suggests, cancer.¹² The goal with both projects was to highlight this limited range of images without, as Kupperts warns elsewhere, “seducing [the viewer] into the fantasy of full identification, the idea that we ‘know’ what her experience is, or even that she knows what it is”.¹³ The imagery, or iconic nature of images in relationship to cancer (the bald-headedness, the dignified dying) functions very differently than imagery in relationship to mental illness, which Kupperts evidences with films such as *The Shining* (1980) and their depiction of the homicidal maniac, and may lead to the direct discrimination of those with mental illness or against the infrastructure which supports them.¹⁴ While *Fun with Cancer Patients* recognised that mental illness has a different relationship with iconography than cancer does, it similarly took as its starting point the proposition that cancer iconography (and its over-reproduction) simplifies the overall experience of cancer. This simplification stifles the expression of those with the illness and creates communication barriers between patients, support structures and medical facilities and this may ultimately affect overall patient care.

While Kupperts does not frame *Traces* as a piece which challenges stereotypical narratives about mental illness, the work — a multi-screened video installation depicting the breath/breathing of a group of participants from Mental Health Day Care Services — refuses to tell a story, depict a narrative, and

¹² Petra Kupperts, *Disability and Contemporary Performance: Bodies on Edge* (London and New York: Routledge, 2003), p.122.

¹³ Petra Kupperts, *The Scar of Visibility: Medical Performances and Contemporary Art* (Minneapolis and London: University of Minnesota Press, 2007), p. 2.

¹⁴ Kupperts, *Disability and Contemporary Performance*, p.122.

demonstrates to the audience that “[t]oo much is unseen, unknown”.¹⁵ This unseen-ness and unknown-ness is at the political centre of *Traces* and *Fun with Cancer Patients*, which both use documentation strategies to refuse the spectator the comfort of thinking they understand, of believing they can easily empathise with an experience outside of their own. By refusing to tell the story of a person with cancer from start to finish, *Fun with Cancer Patients* attempts to avoid the easy narrative dichotomy of Survivorship Story or Bereavement Story, which, as Jackie Stacey suggests, frame most, if not all, of the discussion of cancer.¹⁶ Although a similar pressure is not made or insinuated about mental illness in relation to *Traces*, the work denies the spectator a singular experience to ‘understand’, clearly separating the work as an artistic, as opposed to purely educational or informative, creation. In this way, both *Traces* and *Fun with Cancer Patients* respond to Thompson’s central question in *Performance Affects*, namely, “How do we make work that is permitted not to promise effect?”¹⁷

If the explicit goal of *Traces* or *Fun with Cancer Patients* was effect, then the documentation of the work or the public iteration of the work would demonstrate, simply, how much the various groups of participants learned/ received/grew as a part of the performance-making process. Instead, in both cases, but particularly with *Fun with Cancer Patients*, it was the performance’s *affect* on both the participants and audience (both with mental illness or cancer and those without) that was the goal of the performance, awakening, as

¹⁵ Koppers, *Bodies on Edge*, p.133.

¹⁶ Stacey, p. 2.

¹⁷ Thompson, p. 183.

Thompson writes, “individuals to possibilities beyond themselves without an insistence on what the experience is — what meanings should be attached”.¹⁸

A difference between the two projects is their set-up and relationship to outcome-led practice and how, although both produced affect in their audiences, *Traces* saw this as a by-product of their lengthy group process, and *Fun with Cancer Patients* saw this as the central focus of our relatively-short group process. *Traces* was created between 1997 and 2000, with Koppers working weekly with a group of ten people, first in a Day Centre and following that, in a community arts centre, both in rural Wales, and in collaboration with Tan Dance and Swansea University Adult Outreach Department. For the initial work with the group, an attending social worker was present as was customary with group activities, but the group eventually fell under Koppers’ leadership alone. The project was not necessarily outcome-based and was considered a success by the Day Care Services because they “were running with viable numbers and had a dedicated core group, who had been working together from the start”.¹⁹ To be a part of the group was an option chosen by the members who used the Day Care Services in an unnamed residential centre, and members were provided with up to three events a week as part of the Services’ remit. The performance project was process-based and had the interest of the group members — their growth, their participation — at its centre.

Fun with Cancer Patients differed from *Traces* in that it was managed by myself, through Research & Development funding by the Wellcome Trust, and was specifically focused on developing a methodology to create Interventions (or Actions, as they would eventually be called) with current cancer patients that

¹⁸ Thompson, p. 111.

¹⁹ Koppers, *Bodies on Edge*, p.123.

explored psychosocial realities of cancer. The project sought to use Live Art methodologies to create Actions that would, through their enactment and subsequent documentation, offer new perspectives on the cancer experience. These individual perspectives could then be put together and, as a group of perspectives, allow a complex spectatorial experience for audiences. These Actions, and their documentation, would be responded to by a clinical psychologist and framed for the public as an exhibition/installation communicating these experiences to a general public. While the Wellcome Trust's remit is quite open, and they responded positively to my methodologies (discussed below) as critical for redressing iconography and predictable narratives in relation to cancer, the Arts Award scheme has strict goals for its funding. These goals include to:

stimulate interest, excitement and debate about biomedical science through the arts; examine the social, cultural, and ethical impact of biomedical science; support formal and informal learning; encourage new ways of thinking; encourage high quality interdisciplinary practice and collaborative partnerships in arts, science and/or education practice.²⁰

Wellcome's remit clearly focuses on public engagement and the improvement of the lives of a general public, as opposed to a confined group of participants. Most projects that find collaborators because of what they are (cancer patients, interested community members, etc) over who they are (their specific qualities as performers), tend to be process- (as opposed to product-) focused. In this case, however, the Wellcome Trust's remit was specifically for a product to be created. From the outset, although I admire and value Koppers' approach with her group, it is clear that the set-up to both projects was necessarily quite

²⁰ 'Wellcome Trust Arts Award', *Wellcome Trust*, <<http://www.wellcome.ac.uk/Funding/Public-engagement/Funding-schemes/Arts-Awards/index.htm>> [accessed 28 March 2011].

different. Even so, the care with which Koppers leads and pushes her group in developing *Traces* remains an important inspiration.

The tension between involving participants in a project which is mostly centred on the increased learning and growth of a ‘general public’ (who will be unseen by the participants) created a number of challenges, and it was ethical considerations which inspired the first, and perhaps most successful piece of the *Fun with Cancer Patients* project — the interactive Canvas.²¹ The *Fun with Cancer Patients* website was first envisioned as a recruiting tool, of particular importance as I would not be officially tied to an organisation. Through the website I could pursue potential patient participants through wide postings that could be discovered by a potential participant, pique their interest, and give them avenues to be in touch with me. The *Fun with Cancer Patients* website was created to elicit responses to the question: What would you do, as a cancer patient, that would be useful? The patient participants who would collaborate on Actions would also be asked the same question, and the Actions would be framed to answer them and address them creatively. The question was purposefully left open to allow for suggestions (both in ‘real life’ and via the web) to be practical, emotive, fanciful, impossible to achieve, or anything along these lines. It was also left open as to whom the term useful would apply — they could choose to create something useful to themselves, to their family, friends, or to whoever or whatever they wished. The website’s goal was, without preempting a given response, to gauge what was on the minds of people with cancer, or at least to gauge the minds of people with (or without cancer) who accessed the *Fun with Cancer Patients* website. Although a project website

²¹ Approval for the project was received by the Queen Mary Research Ethics Committee in February, 2009. Laura, the patient participant I will discuss, also agreed to be a part of *Fun with Cancer Patients* and was able to review all documentation before it was placed online. We agreed to use her first name in all discussions.

limits the user or access group to those who use computers, evidence of public engagement with websites such as *I'm Too Young for This* or *Young Adult Cancer Canada* (discussed in Chapter 2) encouraged me to continue a connection with these online sources of sharing and communicating.

Initial designs of the website — with illustrations by Nako Okubo and programme by Chipp Jansen — were informative about the project and provided clear instructions for how people could contribute ideas, virtually, and how they could get in touch, practically. But something was still missing — something for those who were accessing the site. Because of an awareness about the demands placed on cancer patients — physically, emotionally, financially — I didn't want to create just a Call for Participants or just to create a space where people could help me figure out my project. Instead, I wanted to create something fun, emotional, creative, evocative and easy-to-use. Given the ubiquity of the cancer blog and online communities for people with cancer, I decided on a type of viral game that was capable of being both serious and searching, playful and ridiculous in equal measure. The resulting Canvas function consists of over 100 images, each based on a particular item from either cancer treatment or the narratives surrounding cancer. The images, conceived by myself and drawn by Okubo, were derived from both my own experience of illness and the reading of blogs and in particular that of Kairol Rosenthal, which highlights and demolishes the most ubiquitous sacred cows related to cancer.²² Traditional medical imagery, such as x-ray machines, gurneys, doctors, nurses, waiting room chairs, are mixed on the palette with images less-commonly displayed in relation to cancer, such as bed pans, amputated arms, vomit, medical marijuana (or just marijuana) and McDonald's

²² Kairol Rosenthal, *Everything Changes Blog*, <<http://everythingchangesbook.com/>> [accessed 30 March 2011].

french fries. In addition to these two groups of images were added the emotive/metaphysical images, such as the Grim Reaper, a gravestone, a dancer or a yogi, and word bubbles and phrases which I had said or thought in relationship to given moments in my previous cancer treatment.

Responding to imagery like that present inside 'Picture Your Life', the most important aspect of the Canvas function was its malleability and its openness.²³ A stark black-and-white motif was chosen which, although playful in its style, felt radically different than the colourful, pink- or yellow-ribbon-dotted pictures of marathon flyers and fundraising campaigns whose design elicits a given emotion (Figure 1). But the images had to be malleable themselves. If we were to have gravestones and needles and dancing images, it would be important that viewers have the ability to flip and resize the images in accordance to their own interests. Through a simple computer programme, each image can now be independently resized and repositioned. If a person is interested in yoga as a central practice, they can (as one did), place the yoga practitioner on the gurney, with the disco ball underneath his head, as if he were emanating light and peace (Figure 2).²⁴ If a person finds yoga a useless practice, they can (as another did), flip the yoga practitioner on his head with the word 'FUCK' screaming from a megaphone (Figure 3). This simple tool allowed for a myriad of stories to be told via a repertoire of 100+ images.

²³ The *Fun with Cancer Patients* website, a still shot of which is seen in Figure 1, features each of the images as independent FLASH image, able to be guided individually around the space. When the user has created the canvas they want, pressing DONE allowed the canvas to be printed as an independent A4 sheet of paper. Users could then select Print Just For Me, or Print and Share, and those created and "Shared" would be placed on the *Fun with Cancer* blog. The Print Just For Me function was created as an homage to the private box for comments in Bobby Baker's *Diary Drawings* discussed in Chapter 1 and 2.

²⁴ All Canvases submitted (and whose creators chose to "Share Canvas") are featured in *Cancer Cancer Cancer Cancer: collected cancer works by Brian Lobel*, available from April 2012.

The *Fun with Cancer Patients* website allows for an engagement with audiences that are both virtual and unknown — blurring the boundaries between those who are ill with cancer, those who are affected by cancer in other ways (being a caretaker or a widow/widower, as ‘Picture Your Life’ did not particularly have space for), and those who consider themselves unaffected by cancer. Figure 4 lucidly demonstrates the interrelation between people who are physically unaffected by cancer and those who are medically affected by cancer. The Figure, presents all the ‘positive’ imagery available in the Canvas in an epic battle (via enlarged syringe) with all of the ‘negative’, death-related imagery, with the subtitle “take that, Death, not my friend”, thus signifying that the Canvas’ author is — more than likely — not themselves a cancer patient. There is no presumption that all those who submit an idea are currently undergoing chemotherapy or having radiation or surgery, nor is it necessarily important. The website itself becomes — and became for the 200 people who submitted Canvases — a space to explore iconography and express opinions using a tool which remains less tied to predictable or iconic outcomes. While a space for the addition of the text guides individual readings of submitted Canvases (such as in the case of Figures 5, 6 and 7), the potential for anonymity in the submitting of the Canvases allows for an open reading of the work. Responding to art therapy situations where, as Koppers describes, work created by patients with mental illness was considered, rightly or wrongly, “a way into” a patient’s diagnosis, the Canvases associated with *Fun with Cancer Patients* interrupt this process and, through anonymity and open-ended-ness, suggest possibilities without dictating meaning.²⁵

²⁵ Koppers, *Disability and Contemporary Performance*, p.124.

Upon seeing Figure 8 (which was, in fact, the first Canvas submitted when the site went live) I hoped that its creator would want to collaborate on an Action together in person. Something about the Canvas' gallows humour — an image of a skull being prodded by a fork, a knife, a needle, a thermometer and even a tea bag — struck me as shocking, funny and provocative. The image, for me, encapsulated the feeling of a disempowered ill body being prodded under treatment, on the receiving end of catheters, intravenous drugs, and pokes by doctors, nurses and medical students. As an image, the Canvas succeeded in subverting expectations and demonstrates the expansive potential present when images were organised by individuals and able to be flipped and resized. The accompanying text of simply "Eat Me", however, pushed through the imagery in a manner similar to Claire's response to 'Picture Your Life' in that it was bold, provocative and seemed, at least to me personally, as coming from a deep and personal place. When Laura — the Canvas' creator — emailed a few minutes later with an idea for an Action, an exciting collaboration began.

For the sake of this chapter, I will consider two of the three Actions created with Laura as I think they were, of the five total Actions that were created as part of *Fun with Cancer Patients*, the most successful in achieving the project's aims. Descriptions of the other Action by Laura and the two others created with the second patient participant Tansy are still available on the project archive.²⁶ The two Actions I will analyse — *Tommyknockers* and *Guerilla Pub Quiz* — I believe most succinctly highlight the effort to challenge traditional cancer narratives and play with iconography, which made *Fun with Cancer Patients* a success. While the other three Actions — *Yoga at St. Barts*, *Keep a Log* and *Reveal* — led to affective art objects for display as part of the

²⁶ Brian Lobel, Chipp Jansen and Nako Okubo, 'Fun with Cancer Patients Website', *Fun with Cancer Patients*, <<http://www.blobelwarming.com>> [accessed 24 December 2011].

future *Fun with Cancer Patients* exhibition, and provided rich material for reflection by Sue Gessler (the clinical psychologist responding to all of the Actions) they less-pointedly or directly played with the themes explored here. This was influenced by a number of factors — duration of planning/preparation by myself and the participant, emotional and physical distance from their past treatment etc — but most importantly that the pieces had a hard time translating, as Thompson writes, the private Action of the applied intervention into a public iteration.²⁷ Although they were meaningful and well-conceived Actions, that ability to translate the private to the public (through documentation strategies and critical reflection which I will explore here) was not necessarily dealt with first and foremost. I do consider them successful Actions, however, just perhaps not for critical reflection in this context. I do hope, however, to expand conversation about them in future venues.

The process of creating documentation for all of the *Fun with Cancer Patients* Actions came from a reflection on the work of Hayley Newman, and in particular in her work *Connotations: Performance Images 1994-1998* (1998). The work, a series of photographs and accompanying texts taken from a fictional series of one-off performance events, highlights the tension between a performed action and its documentation and was, for Newman, a reflection on “the experience of performing and its archiving as a document”.²⁸ For *Lock Jaw Lecture Series*, for instance, a violent, staged picture of Newman being anaesthetised by a dentist is accompanied by the text “Over the period of a year I was invited to give a series of lectures on my work. Before each lecture I

²⁷ Thompson, p. 34.

²⁸ Hayley Newman in Adrian Heathfield ed., *Live: Art and Performance* (London: Tate Modern, 2004). Available at <<http://www.hayleynewman.com/artworks/show/15>> [accessed 24 April 2011].

visited a local dentist and had my mouth anaesthetised”.²⁹ Newman writes that she never intended the documents to be revealed as ‘fakes’, but given her interest in the “reflexive space between performance and its conventional representation in film, video and text, and photography” and the formalising of experience through documentation, such a distinction seems irrelevant. What Newman does so effectively in *Connotations* is to blur or challenge the line between ‘truth’ and ‘fiction’ and ‘real-life’ experience and performance. Although the Actions in *Fun with Cancer Patients* were very much real events, made by people affected by malignancies, the process of creating and documenting Actions inherently blurs the process between truth and fiction. The one-off or private nature of these events and the subjectivity encouraged by documentation makes the borders between who is affected and who is not affected by cancer more porous — a useful place for *Fun with Cancer Patients* to encourage its viewership to be when encouraging a more inclusive conversation about the cancer experience.

In preparation for the Actions, I worked with Laura, hosting open conversations with her at either a local cafe. Laura was curious about my own path into the work, and most of the first meetings were spent justifying why I wanted to work with others, how I could name a project like this “Fun” with Cancer Patients, and what I was looking to create.³⁰ In this way, ‘cancer’ perhaps, rightly or wrongly, functions similarly to ‘nation’, as defined by Benedict Anderson as an ‘imagined political community’, when he says that “It is [an imagined political community] because the members of even the smallest nation

²⁹ ‘Connotations: Performance Images 1994-1998’, *Hayley Newman*, <<http://www.hayleynewman.com/artworks/show/15>> [accessed 3 February 2012].

³⁰ As a caveat on the acceptance letter from the Wellcome Trust, it was recommended that I considered changing the name of the project to something more reverent. I demurred as the discomfort caused by the name was part of the politics of the work, ideally forcing people to reconsider the tone with which they usually discuss cancer and illness.

will never know most of their fellow-members, or even hear of them, yet in the minds of each lives the image of their communion”.³¹ Because of the flattening of the cancer experience, as previously discussed, all of those who are diagnosed are seemingly placed into one of three categories — cancer patient, cancer survivor, cancer victim — and have a presumed shared interest in celebrating life (as evident in “Picture Your Life”), or fundraising for a cure. While different cancer diagnoses result in extremely different cancer treatments, outcomes and experiences, it was perhaps this shared assumption of communion that Laura looked to my perspective, and I felt as though I could respond to her experience in a knowing way with respect to my own experiences of cancer.

Understanding my perspective was of critical importance to Laura in the building of trust between us, as was describing the process, possibilities and budgets, so that Laura knew how big she could envision her Actions to be.³² While trying not to prevent any ideas, by facilitating the process, I was able to ask Laura more probing questions about areas which seemed of genuine interest to her and contextualised more predictable topics or previously-explored terrain by giving examples of how I’d seen something like it, or touching on it, before. Giving the example of Annie Sprinkle and the removal of her wig (discussed in Chapter 3), I suggested that I didn’t want to only explore hairlessness without first exploring Laura’s interests in it. While this means that the process was not completely democratic, *Fun with Cancer Patients* also functioned with the knowledge of the demands made or physically and

³¹ Benedict Anderson, *Imagine Communities: Reflections on the Origin and Spread of Nationalism* (London and New York: Verso, 1991), p. 5.

³² All of our communication was transcribed and submitted to a blog which remains but is no longer online.

emotional pressures placed on cancer patients with respect to the amount of responsibility she was given. As Koppers describes collaboration, “democratic styles of art making can be threatening to some people in community groups and they might feel uncomfortable and reluctant to accept the responsibility and voice that comes with this style of working”.³³ While I did not imagine Laura to feel ‘threatened’ by taking a leadership role, the goal of the project was to facilitate Laura fulfilling something of use, and less about taking charge of the process. In this way, the project was run in a more-autocratic style, which Koppers also recommends for projects “getting off the ground quickly and effectively, and to set up a comfortable framework”, which, given that Laura was finishing treatment, re-starting work, and negotiating this new post-cancer life, seemed of interest to both her and myself.³⁴

If, presumably, Laura was still only interested in creating an Action around losing her hair, I believe I would have been responsive and worked towards an Action engaging with that subject area. There are, of course, limitations to this kind of leadership style — if facilitator and participant are not honestly communicating about intentions and goals — but in this specific occasion, the style seemed to be appropriate and welcomed. While we attempted a more succinct process using this style, the process (perhaps because of my and Laura’s natures), became more democratic and open. Having had the roles and expectations determined during that introductory period of autocratic leadership, however, allowed for clear communication about roles, expectations and goals. Laura and I communicated for three months

³³ Koppers, *Community Performance*, p. 101.

³⁴ Koppers, *Community Performance*, p. 96.

before finalising the aspects of the cancer experience to explore via Actions: the changing meaning of words after cancer diagnosis and memory loss.³⁵

Tommyknockers Tommyknockers, Knocking At My Door

An automated slideshow shows a group of five people, never identified, in Kilve (near Somerset) walking along the beach covered in large white rocks. They are laughing, water is running and the woman leading the charge is carrying a strange purple doll. A voice, presumably hers, begins describing that she created the doll on her sewing machine, consciously giving it lopsided eyes, a crooked mouth (as opposed to a smile) and stitches over the breasts and “lady bits”. “I quite liked sewing it”, she says, “it was like sewing somebody up”.³⁶ A closer shot of the doll reveals that it is covered in words, written in black marker, including ‘breast’ and ‘scar’. While images flash between the group smiling and looking more pensively at the doll and handsome landscape, her voice describes the doll:

I wrote words on it. Words that now seem to have a different meaning I guess, or words that, when other people say them, I say *oh, hello...* Words that people said to me whilst I was ill that annoyed me. Everything just really associated with having cancer, I guess...

The pictures return to the landscape, capturing the group drinking beer and sitting quietly on the rocks. Images of three disposable grills appear on the rocks, and a man’s voice says that he loves the sound of lighter fluid. The women begin to write “Burn Baby Burn” on the rocks in orange chalk. A close-

³⁵ The third Action created — Yoga at St. Barts — dealt with anxiety around follow-up treatments and involved Laura having a one-on-one yoga session with instructor Angelika Groehmann in the centre of the St. Bartholomew Hospital’s complex, where Laura had been treated. The Action was audio recorded by Andrea Salazar and live drawings were taken by Olga Raciborska.

³⁶ Video available at <http://www.youtube.com/watch?v=Ilji3PIAEYc> [accessed 7 April 2011]. Also featured on *Cancer Cancer Cancer Cancer Cancer*, cited above.

up of the doll now reveals more words: 'Surgery', 'Boobies', 'Procedure', 'Nipple', 'Handful'. The woman's voice says that she wants to burn it now...

As Laura stands in front of the group, there are giggles, and slight discomfort seemingly drawn from the need to give an introduction to an audience of only four people. It is quiet except for the sound of crackling fire. "I just want to say thanks everyone for coming" she says, "I know this is a bit of a weird thing". Silence. "Yeah". More silence. "I think I might cry" she says, with an image of her and her partner, Phil, and her sister, Tori, standing in front of a small fire. There is a protracted silence once more. "Anyway, here we go... goodbye cancer". And the doll is thrown. There is laughter and conversation about the presumably toxic contents of the now-burnt doll stuffing. The doll disappears instantly before a final image can even be taken by Christa Holka, the photographer. Phil is heard saying, "It just kind of rolled over..." And the video ends.

Laura had wanted her first Action to incorporate a great number of things including a thank-you to her partner and sister and a strange ritual exorcising the cancer from her body, but the conversations always came back to, or featured most prominently, a reflection on how words, post-cancer diagnosis, have extremely different meanings. Laura thus took the main inspiration for her idea from a chant from her days in drama school which repeated the line "Tommyknockers, Tommyknockers, knocking at my door", a feature of the horror film *Tommyknockers* (1993), based on Stephen King's 1987 novel. A once simple chant became a minefield of discomfort, with Laura describing the power of the word 'knockers' to remind her of her physical difference after having a mastectomy. Although the chant never made it into the final Action, the doll was crafted to look like a Tommyknocker, an alien life form from the film.

In order to contextualise each of the Actions into a broader conversation about the cancer experience, the Action ideas — as they were shaped — were reported to Sue Gessler to see if Laura’s experience was extraordinary or quite common. Gessler, a clinical psychologist working at University College London in gynaecological cancers, and I began our collaboration after meeting at IPOS (International Psychosocial Oncology Symposium) in 2009. The goal of our work together — aside from just finding a way to fit inside the Wellcome Trust’s remit of having artists and medical professionals work together — was to use Gessler’s extensive experience researching and speaking with women with cancer to probe whether each Action represented a rare personal experience with cancer, or if other patients experienced the same realities. We hoped that *Fun with Cancer Patients* would incorporate both rare and more common personal experiences with cancer.

After the Action was completed, documentation was shown to Gessler after which she and I wrote a 250-word statement to explain and probe the Action further, without having such an interpretation or analysis be a part of the Action itself. Not only was this important in order to fit the project into the remit of Wellcome Trust Arts Awards — which ask artists to pair with medical professionals — but it was important for us to put our thinking into a broader context (a public iteration) in hopes of seeing if these very personal issues were relevant to others experiencing cancer. Instead of psychoanalysing Laura or Laura’s Actions — as might be expected from a psychotherapist giving expert advice — Gessler was, instead, asked to add professional context. Do many other patients experience difficulties with the language of cancer? How do doctors diagnose cancers without entering the minefield of psychologically problematic semantics? Is this an aspect of psycho-oncology which is well

documented or discussed professionally? In this first case, Gessler felt that the area of exploration done with the *Tommyknockers* Action was quite pertinent to a larger group of cancer patients outside of Laura's experience, saying:

“Surgery’, ‘Recovery’, ‘Procedure’, ‘Negative’... What’s going on with the language is that you’ve got words which are normally so neutral and they suddenly become charged... A classic one is ‘Progress’. The word ‘Progress’ is normally quite good in the outside world. When a doctor says that your disease is progressing, you think “Oh Great!” whereas Progressive Disease means that the disease has progressed during treatment — that it has continued growing while we’ve been giving chemotherapy.

Same with positive and negative. Usually positive is a positive thing, and negative a negative thing, but not so in the case of diagnosis. An ordinary word is taken and given an exact meaning in their world, and it is pulled around willy-nilly for you, the patient.³⁷

Much like my own work with language in *BALL* (in which I define 15 terms around and explore their alternative meanings in cancer conversations) *Tommyknockers* effectively highlighted the experience by which cancer patient needs to learn an entirely distinct language, a process I termed as overwhelming, and which Laura saw as downright offensive in many cases.

Gessler's statements also took on professional issues, mainly her explanation of using PTSD (post traumatic stress disorder) methodologies when providing counselling for people with cancer.³⁸ While not all psychoanalysts use a trauma model when working with cancer patients, Gessler employs it frequently:

With trauma, words stop having their symbolic meaning. The word trauma comes from a piercing through armour — it means that something gets straight to your core. One of the things that's really odd about cancer is that seemingly-symbolic words become literal things. For most people, cancer comes up symptom-free. You go in with something worrying and then this doctor says these words

³⁷ Full statement available in Appendix C and accompanying the video on YouTube.

³⁸ A professional biog for Dr. Sue Gessler and her psychological approaches are here: <<http://www.uclhwomenscancer.com/biogs/sue-gessler>> [accessed 1 November 2011].

to you and those words are ‘radiotherapy’, ‘surgery’, ‘chemotherapy’. Suddenly there are these words — for which you previously have no referent — which become things inside you doing terrible things.

Gessler here demonstrates that Laura has enacted many of the points, unknowingly to herself, made by Jackie Stacey in *Teratologies* discussed in previous chapters, particularly in relation to how the usage of language around cancer changes one’s relationship to one’s own corporeality.

The statements by Gessler were created, much like exhibition labels, to give explanation of the Action without analysing the state of the participants. This was precisely a function of wanting there to be a public dissemination of the material that was contextualised alongside other people’s experiences — of which Gessler is an expert. While I was delighted with Gessler’s thoughtful consideration and generous contributions of knowledge, it was important for me that Laura’s Action be developed without previous input from a medical or psychological professional. In this way, I attempted to protect Laura from what might be perceived as a overpowering medical system (as evidenced previously in relation to Lorde and Spence) which would determine *how* she needed to experience cancer or how to work with *Fun with Cancer Patients*. Additionally, having *Dr.* Gessler’s text (I specifically use her title in this sentence as, rightly or wrongly, her professional credentials made her a different kind of expert in this conversation) allowed the Actions to fit into the Wellcome Trust remit of supporting formal and informal knowledge without insisting that Laura be the individual providing the teaching materials.

For Laura, the Action remained a one-off event, a family car trip with two individuals who documented the action (Christa Holka, the photographer, and myself who audio recorded the Action). The action remained otherwise free from an audience with expectations of narrative or who would be looking for

signs and symbols relating to previous cancer stories. I didn't ask Laura to make a speech while on the beach, it was just something she felt had to be done. At no points was Laura asked to celebrate her survivorship, or bemoan her body, nor was she asked to create a story with a beginning, middle and an end. The revelation of cancer into the narrative of the video is a quiet one, focussing more on what the words on the doll meant, and less on how it all made her feel.

The creating of emotional distance for the audience is a conscious effort; not only does the documentation remind the audience that they were not there on the beach in Kilve, but it also reminds them that they are not fully privy to the emotional secrets of a person with cancer. Using photography as the documentation format even more so highlights this distancing, in that audience members can't always track what the audio recording is demonstrating thus asking audience members to piece together the audio with the photographs themselves. The piece never claims to be Laura's full story of cancer, but rather remains a piece about the experience of having a change in perception of language after Laura's diagnosis. There is no call for empathy or sympathy and the Action's inherent privacy (it existed just for Laura and her intimate relations) demonstrates that not only is *Fun with Cancer Patients* not a fundraiser as much work related to cancer is (or is framed as) but that it does not propose to help directly anyone but those present.³⁹ Although there is strength in community (such as with Walk for Life) there is something equally powerful in

³⁹ Although *Fun with Cancer Patients* was very much a non-profit venture, we chose a .com over a .org to reinforce this point. Although many options are presented when creating a domain name we felt that a .com (or a .co.uk which could have also been used) was less reminiscent of cancer charities like macmillan.org.uk, cancerresearchuk.org or even wellcomecollection.org. The goal was to focus on the first impression of the website user's interaction, and followed the lead of stupidcancer.com or realtimecancer.com to create the boldest impact, and to draw on the commercial appeal and recognition of the .com. I do recognise, however, that distinctions between domain endings may function in more nuanced ways than presented here.

knowing that your life does not need to inspire others, raise money for others, or by its virtue be something which needs be sanitised and presented literally for consumption. In this way, *Fun with Cancer Patients* achieves Frank's goal stated in *The Wounded Storyteller* of shifting the "dominant cultural conception of illness away from passivity — the ill person as 'victim of' disease and then recipient of care — toward activity".⁴⁰ I argue that *Fun with Cancer Patients* goes even farther than Frank's suggestion — which claims that the telling of one's story affectively moves that person from passivity into activity — by putting Laura's story in dialogue with non-effect. Because Laura was not asked to have her story teach, inspire or *do* anything, *Tommyknockers* — as an action conceived by herself and produced by others — empowered a truly active moment.

While I do not appear to a significant extent in any of the documentation for *Tommyknockers*, it felt critical that I appear in various shots and that my voice is present as part of the audio soundtrack. From the title of *Fun with Cancer Patients*, to the facilitation of the creation process, to hiring the car, to the edit of the documentation, the series derived from my own preoccupations with cancer, my own tastes and my own areas of interest. In this way, *Fun with Cancer Patients* diverged from Kuppers' definition of community performance because of my own investment in a product- (I prefer Action-) oriented process where I was comfortable guiding the conversation. Although I believe I created "spaces and times for [participants] to create their expressive material", as Kuppers writes about community performance, I was acutely aware of the political territory I wished to explore, namely that of moving cancer patients

⁴⁰ Arthur W. Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: The University of Chicago Press, 1995), p. xi.

outside of frames of pity and into positions of responsibility and power.⁴¹ While I hope that I would remain open to ideas that didn't coincide with my interests, I am well-aware of how powerful a guiding force even gentle facilitation can be.

In order to highlight my own perspective in creating the *Fun with Cancer Patients Actions* and to alert viewers to the subjective nature of the narratives I was facilitating, I decided to put myself into the frame of the photographs and pieces similarly to Joe Sacco, author of the graphic novels *Safe Area Gorazde* and *Footnotes in Gaza*, which detail his reporting on the Balkans and Palestine respectively.⁴² By placing himself in a frame on each page, there is a constant reminder that the reader is seeing these areas of conflict — refugee camps, destroyed homes, prisons — through Sacco, who is neither a local nor someone directly affected by the conflicts themselves. In a particularly exemplary incident in *Palestine*, Sacco's journey with Sameh, his translator and guide, reveals that Sameh has been demoted at his job because of his relationship with Sacco. While Sameh speaks, the viewer can see Sacco struggling with the ethics of his work which requires Sameh's help. Sacco's internalised conflict (wanting the pictures, the contacts, the stories) is shown through thought bubbles and framed with wordless reflection, and the reader is reminded that the information presented in the novel comes at a price and from real people, and that this is a process, the ethics of which need to be consistently reflected upon. In a harshly ironic moment, Sameh shoos schoolchildren away from the grave of Hatem Sissi, the first man killed in the Intifada. "Sameh shoos the kids out of the way." Sacco writes "I want the kids *in*

⁴¹ Koppers, *Community Performance*, p. 3.

⁴² Joe Sacco, *Safe Area Gorazde: The War in Eastern Bosnia, 1992-1995* (Seattle: Fantographics Books, 2000) and *Footnotes in Gaza* (New York: Metropolitan Books, 2009).

the photo, but anyway..."⁴³ In this brief moment, Sacco's presence in the screen allows him to have a respectful relationship with Sameh while simultaneously recognising the journalist's or photographer's desire for a more dramatic, children-playing-on-grave picture. The relationship between Sacco as casual, but interested, outsider and the people about which he writes has changed since Sacco and his graphic novels have become a more recognised political force, documenting the lives of often-overlooked people and taking an empathetic stance on his subjects. His constant presence in his work, however, allows the change in his stature — and people's investment in telling him their story, accordingly — to be documented and incorporated into the work itself.

For myself as a performance maker and person who formerly had cancer, this relationship between insider and outsider is complex. While I never claim, or could claim, to understand Laura's individual, embodied experience of cancer, my own experience was drawn on heavily during the conversations that led to the Action. Although I consider myself open to all sorts of Action ideas, had Laura said "I want to run a 5k race to raise money for cancer research", I probably would have been less than enthused as it feels like a trope which already exists in popular discourse around illness, and for which my artistic facilitation would not necessarily be needed. This lack of enthusiasm may have led to me not facilitating the further conversation that could have revealed that perhaps running a 5k or a marathon is useful because it reflects on the body as a changed, yet still powerful, being, or reflects on how cancer patients often feel disconnected from their bodies and that exercise is a methodology to reconnect the person with their entire body, changed parts and all. Recognising my own interests and the fact that my background was used to help inspire the Action

⁴³ Joe Sacco, *Palestine* (Seattle: Fantographics Books, 2002), p. 220.

ideas, placing myself inside the frame of the video felt essential. Although only her voice is heard, the presence of photographer Christa Holka also works to reveal the funny/awkward/special nature of the Action, removing an exclusivity from the activities and allowing the content to be more straightforwardly presented. Had the piece been framed without myself or Christa, and focused only on Laura's speech and the burning of the Tommyknocker, the video might be in danger of romanticising the experience of cancer as an experience which connects families and brings people to exotic and beautiful locations, similarly to the pictures present in 'Picture Your Life'. While there is nothing inherently offensive or dangerous in those images, it is their curation into a story line and overall message which prescribes given meanings that have already been explored and exposed (by Ehrenreich, among others) as limiting.

Tommyknockers has three critical elements which help confer meaning as a performance or Live Art piece: the Action, the documentation and the reflection. The first element is the Action itself — the car trip to Kelve and the burning of the effigy — which, although effectively only seen for a small audience remains an intimate work which communicated an experience between one body and another, or another four bodies. Looking towards Erving Goffman's work on performance in everyday life, and defining performances as "all the activity of a given participant on a given occasion which serves to influence in any way any of the other participants", *Tommyknockers* can be seen through multiple lenses.⁴⁴ Specifically, in various arrangements, the piece can be seen as a performance by Laura in front of her family, a performance by the family, performing family, in front of Christa and myself, a performance by all five bodies present for an audience of ourselves, or an performance by all three

⁴⁴ Erving Goffman, *The Presentation of Self in Everyday Life* (London: Penguin, 1959), p. 15.

of the family members, or indeed all five of us, for an exhibition audience they/ we may never see. Each configuration speaks differently to how cancer and cancer survivorship is discussed and framed in current discourse — one body in front of another body — and hopefully asks audiences to wonder about their own positions, if they are a person with cancer, or they are not a person with cancer, or if such a distinction is important. The blurring of the lines between the affected and unaffected feels at the heart of *Fun with Cancer Patients* as a political work which attempts to de-emphasise the emotive power of the word cancer, and allow it to be less encumbered by expected narratives placed on cancer patients which frame their experience.

The second aspect, the documentation, ideally intervenes in how cancer is discussed and presented. Each of the Actions is documented in a different mode, one that felt relevant to the Action itself and one with which the patient participants would be comfortable. For the second Action, the one-on-one yoga session, Laura did not feel comfortable having her photograph taken — feeling less comfortable with her body and being a novice at yoga — and so live drawings and an audio recording of the yoga instruction were taken. In the case of *Tommyknockers*, Laura felt comfortable with Christa and myself taking photographs and audio respectively, but felt that having a video camera present would make her feel too much pressure to pose or act in a certain way. Because Laura and Christa had met previously, there was little concern that Laura would feel such discomfort, and Christa's presence as an unobtrusive photographer was well suited for the task. For the audio soundtrack, a high quality microphone was brought and left on for most of the day. Extensive editing was later carried out to create the 5.5 minute video piece out of the sound and images together.

The documentation is critical in bringing the Action to a broader public, one of the criteria for the Wellcome Trust funding their projects, and an interest for myself as a performance practitioner. In a manner similar to the conversational nature of *BALL, Fun with Cancer Patients* is about evidencing experience and presenting it to others for educational, intellectual and emotional reflection. What the automated slideshow and soundtrack do is disrupt the viewer's expectations more than might be done with a film by highlighting what is missed in between the photographs such as dramatic shifting plot lines (as might be seen in *Terms of Endearment* or even *An Appreciation*) or recognisable monikers of cancer. The viewer is allowed to be drawn in by the beauty of the scenery and need not be waiting for the big cancer moment — as most narratives have — to come into the screen. There is something also quite powerful about the 'big cancer moment' (the speech by Laura) that appears as a voiceover with static and non-crying images, with her crying purposefully omitted. As previously discussed, such images, continually shown, lend to the misinformation that cancer is a singular experience that looks like 'this' or creates reactions like 'that'. While it's true that Laura did, in fact, cry, the absence of an image allows for an opening up, instead of a closing down, of meanings and interpretations, whereby audiences can think about what crying might mean (to Laura, or to themselves) without its image being presented. This absence is informed by the productive silences and absences discussed in Chapter 1 in relation to Sontag's writing or Baker's decision to put a box for gallery feedback in *Diary Drawings*. Sontag's theorised silence (and actualised silence in the writing of *Cancer and Its Metaphors*) and Baker's feedback box motion to silence and non-disclosure as an integral part of the experience of illness. Although Laura chose to disclose her more personal self

on Kilve Beach, in communicating this disclosure to a remote audience (the audience of the documentation), the video's silence allows the unclear depiction of the cry to be interpreted in many different ways by the remote audience members.

The final critical aspect of the Action is the reflection, done by myself and Gessler. Although the *Tommyknocker* Action can be interpreted as being about many things including family support and post-treatment uncertainty, it was our desire to frame the central interpretation of the pieces around a given theme. Not only would this allow for clarity — knowing what the piece was 'about' — but it would also ensure that the message of the piece was clear and specific. As I have been previously explained, so much of the iconography and narratives around cancer allow for generalised interpretations which lead people to clump all treatments and diagnoses together. Although the piece does not intend to pander just to people's ignorance about such things, *Fun with Cancer Patients* recognised that we are all affected by such a clumping and flattening of identities and experiences. Giving the piece a specific 'This is what this is about' feeling prevents the audience from looking for whether the patient lived or died at the end, or from wondering where the fundraising pitch would fall. While one must be critical of simply deferring to medical or psychological authorities to say what is what, having Gessler's voice present allows a singular message of the Action (about word meaning or memory loss) to be highlighted and expanded upon. The reflection present compares Laura's experience with some other patient's experiences (as discussed by Gessler) without policing Laura's individual behaviour during the Action. It also, by widening out the scope of the conversation, implores audiences to realise that Laura is not necessarily representative of all cancer patients. She may have shared

experiences, but she may also have experiences with cancer that are uniquely hers. I hope that the process of *Fun with Cancer Patients* shows that experiences are not predetermined and certainly not as formulaic as responses to cancer may appear to be in broader cultural narratives, such as the ones I have outlined at parts of this thesis, especially in Chapter 3.

As we cleaned up the disposable grills and finished our beers, I turned off the audio recorder and Christa stopped taking photographs. At supper, we sat quietly as a group of people who had just completed something that we didn't quite understand. What would these pictures look like? Was it bad that we didn't do the ritual exorcism? Should Laura have prepared something more to say? Was it weird that we spent only 45 minutes on the beach when it took three hours to drive there? None of these questions had to be answered at the time; we just had to sit and eat and drink, and know that we have driven to Kilve, burned an effigy, had a beer, spent time together and finished. With so much about the cancer experience being determined — high blood counts mean this, treatment courses look like this — perhaps this nervous, unknown energy is a way to resist such movement. And in the documented example of this unknown energy, perhaps audiences can find power or comfort in making their own meaning to their own Actions.

The Guerilla Pub Quiz

A shaky video captures an unusual intervention at a pub. At Off-Broadway, a busy pub in Hackney, east London, the last-call bell is rung as Laura steps up to a microphone. She welcomes everyone to the Guerilla Pub Quiz and explains that this is a part of a project called *Fun with Cancer Patients*. “That word has entered the room”, she says, “Yes people, I am a cancer patient, but don't

worry, this is going to be fun”.⁴⁵ The directions are straightforward. Laura first asked the teams to give themselves a name that could serve as an alternative name for cancer (there are several groans from the bar); Laura then precedes to ask 10 questions about cancer. Some questions are statistic based (e.g., “On average, how many people a day are diagnosed with breast cancer in the UK?”) while others are based on Laura’s personal experience (i.e., “Which one of my boobs is fake, left or right?”). The audience goes from laughing to silent in quick succession, and Laura — after asking about baldness — seems to recognise which words/ideas cause the different reactions. Her penultimate question is to identify the author of a quote, the answer of which, in the edit of the final video, is never revealed. The quote (by Dr. Seuss) goes unanswered by most teams and catches the audience off guard with its poignancy:

I’ve heard there are troubles of more than one kind,
Some come from ahead some come from behind.
But I’ve bought a big bat, I’m all ready you see,
And now my troubles are going to have trouble with me.⁴⁶

When the answers are revealed there is a somewhat uncomfortable mixture of highly competitive pub quiz energy and reflection on the severity of cancer. As Laura states the average number of women diagnosed with breast cancer in the UK in a day is 125, a voice from the crowd shouts “Oh, we were close” before Laura responds “Yes, you were close” with an irony in her voice which recognises the exceedingly high number of women affected by breast cancer. By the time the ‘which fake boob’ question gets answered, the audience appears less uncomfortable with the set up, and a celebration ensues when

⁴⁵ Video available at: <http://vimeo.com/10527523> [accessed 20 April 2011]. Also available on *Cancer Cancer Cancer Cancer Cancer*.

⁴⁶ Dr. Seuss, *I Had Trouble in Getting to Solla Sollew* (New York: Random House, 1965).

Laura reveals that most teams answered correctly. “Someone wrote ‘the middle’”, she adds with a smile.

To conclude the Action, Laura speaks to a fully-hushed room:

During my treatment last year, I found that my memory isn't as good as what it was — due to all the drugs and that. So, as homage to losing my memory, the winners are those who got the most wrong.

As one group member from the winning team comes to the stage, Laura announces that the prize is a wig, identical the one she is wearing, the wig she wore when she had no hair. She ends with a hearty “Cheers everyone” and the crowd cheers.

Although not crafted intentionally as so, *Guerilla Pub Quiz* felt like the polar opposite of *Tommyknockers* in that it's public, aggressive and heavy with cancer facts and figures. In our introductory conversations, Laura had talked extensively about memory loss, or ‘chemo brain’ as many call it, and questioned whether it was a real thing, or a convenient excuse for not paying attention. While, much like with *Tommyknockers*, Laura had additional goals for this Action, we decided to hone in on chemo brain as the central theme and allowed other aspects — a desire to introduce humour in cancer, a desire to discuss her changed body in front of others — to accentuate and deepen the performative exploration. In conversation, Laura often used the word ‘loser’ in relation to memory loss, i.e., she felt like a loser because she wasn't able to remember and function as well post-treatment as she had previously. With this in mind, the answer to the questions “What would you do that would be helpful?” became “I would celebrate my memory loss”. And celebrate she did. By crafting a competition in which the winners are those who answered the least amount of questions correctly, Laura succeeded in flipping, even tongue-in-cheekily, the expectation that to have memory loss is a bad or tragic thing. To remove

judgement around that memory loss and to recognise that memory loss is a part of the cancer experience feels at the political centre of *Guerilla Pub Quiz* and to *Fun with Cancer Patients* more generally.

The Action of the *Guerilla Pub Quiz* was very much a performance, featuring Laura and her stand-up comedy persona, which she has been developing in the past few years. It was precisely her engagement with the stand-up comedy format (a deadpan voice, a casual approach) that made the conversation about cancer seem all the more subversive. She presented cancer material without the expected reverential hush and, recognising the usual severity around the word, provided an opportunity for audience members to rename cancer, creating a method for them to avoid hearing the word. “Last year I was diagnosed with kittens, for example” she says, recognising the overwhelming nature of the word ‘cancer’ to both flatten experience and prevent people from listening to what she is saying. But ‘kittens’: everyone will listen to a conversation about kittens.

The Action did not shy away from the personal and the difficult emotional territory but rather negotiated the usual terrain of the cancer narrative in unexpected ways. Instead of highlighting hair loss as a traumatising event, Laura highlighted it as an experience that is complex and relational: “When I was bald, I was compared to a certain person at work, by a child... Name that person”, she remarks in the video, allowing the story of hairlessness (often the focus of other stories) to be a given in her exploration. Her question of “Which one of my boobs is fake, left or right?” is a complex question for an audience to hear, in that it is said so proudly and with so much guts that, watching it, you almost forget that this is her real body she was discussing and putting in front of an audience for consideration. The Action reveals both a body completely

clothed while remaining incredibly exposed, allowing an audience (both in the pub and watching the documentation) to question how they are watching and judging a body that is in front of them. Allowing an audience the opportunity to reflect on their own gaze is a generous action of Laura, who presumably meant to redress others' curiosity with her bold action.

Her final question, "What percentage of women who find and treat breast cancer early will be cancer free in five years?" — in relation to this audience — was also fraught as this was not a theoretical body or statistic that is being discussed. For the audience members at the pub, the statistics were talking about this living body in front of them, a realisation that allows them to reflect on Laura's mortality as well, perhaps, as their own. When later she announced that the answer to the question is 96% saying "I hope I'm part of that percent", the moment becomes less about the numbers themselves (which, as previously discussed can be meaningless or misleading) and more about watching Laura's wishful thinking. The putting together of a young, healthy-seeming body and a discussion of cancer in a pub, ideally, created a rare space for reflection for the audience members.

While the *Tommyknockers* Action remained private, the public nature of the *Guerilla Pub Quiz* was perhaps its most notable feature. Although the audience at the pub contained a handful of invited guests and friends, the overwhelming majority of those in the pub were not aware that any event would be taking place. Much like my own performance, *An Appreciation, Guerilla Pub Quiz* succeeded in bringing cancer to a public situation which is generally cancer-free, in hopes of decreasing the power of the word and integrating cancer into everyday conversation, an alternative to reserving it for hushed

moments. Nato Thompson, in his introduction to *The Interventionist* describes the political power of such performative interventions, writing that they

bring political issues to an audience outside the insular art world's doors. They [the tactics of intervention] appear to a viewer who is confronted by an increasingly privatised and controlled visual world. Humor, sleight of hand and high design are used to interrupt this confrontation and bring socially imperative issues to the very feet of their audiences.⁴⁷

The integration of cancer into everyday conversation is an imperative mission, but not always a painless process, and in a handful of cases, audience members at the pub were quite unnerved that the performance had happened. One couple, in particular, asked to donate the money equivalent of their free drinks (drinks were provided for everyone) to a cancer charity. When Laura explained that *Fun with Cancer Patients* was not a charity, the young duo appeared not to understand. How could a cancer project not be related to fundraising? After the Action, aware of the presence of this couple directly inside the pub, Laura smoked surreptitiously, afraid that cancer not being a fundraiser and watching a cancer survivor smoke would be too much for them to bear.

The documentation of the *Guerilla Pub Quiz* was seemingly more straightforward than with *Tommyknockers*, in that Laura was comfortable having her stand-up performance recorded, and it felt appropriate to arrive with video cameras, which can be as intrusive as perhaps the Action was. It was, however, in the editing that a decision was made to cut out a song that Laura sang as part of the performance. After the answer sheets had been tallied and before the winners were announced, Laura made impromptu thank you's to me and the *Fun with Cancer* team (which on that day included Christa, videographer

⁴⁷ Nato Thompson, *The Interventionists: A Users' Manual for the Creative Disruption of Everyday Life* (North Adams: MASS MoCA Publications, 2004), p. 14.

Na'ama Yuria and technical producer Andrea Salazar) before singing a song to her fiance Phil. The song, a cover of Radiohead's *Creep* on the ukelele, was probably the most beautiful part of the Action. Looking around, a handful of people were crying and others just stared silently at the sheer unironic, loving, thankful emotion that was placed in front of us.

As beautiful as the live moment of Laura's song was, the song is a departure from the Action title of "Celebrate your memory loss" and was edited as a separate video work not to be included in the video for the *Guerilla Pub Quiz*.⁴⁸ This decision was made in part by Laura (perhaps a function of discomfort around singing) but mostly by myself, wanting each Action to be particularly focused around one aspect of the cancer experience. Although it is impossible to separate fully any one aspect from another (the memory loss from patient support or body discomfort) as all are connected in various ways, I felt strongly that the love-song-to-partner would, dramaturgically, overwhelm the documentation and create too strong a narrative. The pub quiz itself, with its play on tone and reflection on memory loss, provides more than enough material for contemplation and education. This quite-dramatic deletion and edit, however, goes unnoticed in the short film. While *Tommyknockers*, as a photo slideshow, highlights the viewer's non-presence in Kilve, *Guerilla Pub Quiz* simply allows Laura to retain control of her narrative, and keep the song she sang as a one-off event. Instead of *Fun with Cancer Patients* forcing Laura to repeat and repeat and divulge, the set-up allowed for multiple layers of comfort and disclosure, by the patient participants, to be explored. From my perspective, the deletion of the song (reiterating a Phelanian bias against documentation's ability to capture live experience) prevented the video from

⁴⁸ Video of 'Creep' available at: <http://vimeo.com/10547841> [accessed 25 April 2011]. While the video remains online as per Laura's permission, it will not be featured on the DVD.

being overwhelmed by narrative or expectant conversations about cancer while allowing the Action to contain these elements that were critical to Laura's experience.

The final element of the Action, the reflection by Gessler, allows the pub quiz to speak to larger issues related to cancer (which might be of interest to medicine and, specifically, the Wellcome Trust's remit) while freeing Laura or myself from the burden of representation. Similar to Gessler's reflection on *Tommyknockers*, the statement she crafted presumes an imagined community of people with cancer (as varied as they might be) experiencing similar physical or mental changes. Instead of starting directly with the physiology of 'chemo brain', Sue first draws attention to why 'chemo brain' is such a misunderstood or under-researched phenomenon:

Chemo brain is really really interesting because there's been a long history of patients complaining about it and people rather ignoring it because it's not 'sinister'. Everything to do with cancer is ignored if it's not about the illness itself. These things were seen as small problems on the way.⁴⁹

Identifying the biases inside the medical profession helps the viewer (in this case, the viewer of the online video) think more critically about medicine and understand that it too is a subjective process, affected by funding priorities and the current cultural atmosphere. If, in previous cancer treatment, the goal of medicine was to keep the patient alive at any cost (as Gessler suggests), a phenomenon like 'chemo brain' may not be a priority of cancer research.

But chemo brain, if not a scientific fact, is definitely a current part of cancer conversation. How much a part of the conversation, and being talked about by whom, however, is also a subjective issue. A guest statement from University College London Hospital Head Nurse (Oncology) Anne Lanceley,

⁴⁹ Full statement available in Appendix D and online at 'Guerilla Pub Quiz', <<http://vimeo.com/10527523>> [accessed 22 January 2012].

who I interviewed in hopes of gaining a professional medical context from a nursing perspective, elucidates this point quite nicely:

I've been caring for people with cancer for 30 years and only recently heard the term Chemo Brain. I think it's generated by people with cancer talking to each other. It's a cancer-sufferers or -survivors terminology which is not a medical language. It seems empowering that it comes from the grassroots and not that it originates from a doctor.⁵⁰

The 'grassroots nature' of the chemo brain conversation relates to and frames Laura's Action by positioning Laura's experience as one of many patient experiences, perhaps against the medical profession or perhaps redressing the absence of research or solid scientific answers to this embodied phenomenon. Laura, in the *Guerilla Pub Quiz*, takes the memory loss as a given, and seemingly does not need to explain whether this thing is real or where it has come from. By having Laura speak from her own experience exclusively, and adding contextualising statements to the video documentation by Sue Gessler and Anne Lanceley, the audience to *Fun with Cancer Patients* is able to think more critically about the language of cancer experience and the supposedly definitive nature of scientific knowledge. By slowly expanding the narrative around cancer to include voices from nurses and grassroots patient advocates, such reflections work to change the overall culture of cancer, which currently privileges doctors as all-powerful.

Perhaps the main reason for the contextualising statements being added after the Action and without Laura's participation was that this allowed the Actions to feel like precisely that, an Action. Had we been constantly reflecting throughout or conducting surveys with rigid questions throughout the process, the atmosphere of making and doing collaboratively may not have been

⁵⁰ Full statement available in Appendix E and online at 'Guerilla Pub Quiz', <<http://vimeo.com/10527523>> [accessed 22 January 2012].

possible. While the documentation and statements allow the research of *Fun with Cancer Patients* to come to the fore, they do so only in hopes of reducing the pressure placed on the Action itself. As previously mentioned in relation to the couple not believing *Fun with Cancer Patients* was not a fundraiser, the pressure to create something useful and proactive is very strong — and maybe particularly strong for people who define as advocates or applied arts practitioners. Although this pressure may be derived from a culture that looks to pity people with cancer (thereby separating them out as different), it remains very real indeed. The mixture of Action, documentation and reflection allowed *Fun with Cancer Patients* to respond to individual desires, outside pressures and, perhaps, the individual desires to appease those outside pressures.

Fun with Reflections

Reflecting critically on *Tommyknockers* and *Guerilla Pub Quiz* makes me feel both confident and unsure about my conclusions, and in equal measure. While I am enthusiastic by the final — in these two cases video — documentation created from the Actions, and feel validated by Laura's pride in the projects and Sue Gessler's professional reflection on the works, I am also wary about drawing definitive conclusions from the work. Or at least *too many* definitive conclusions. The Actions, and even the *Fun with Cancer Patients* project itself, were developed from personal experiences, reacting to what I had experienced myself and heard in conversation with Laura and others, as opposed to an extensively researched biomedical or psychooncological processes. While my reading on cancer and participation in conferences over the years has highlighted for me the importance of thinking about 'chemo brain', the

importance of yoga, support systems and the like, there was (and is) no checklist of 'Psychosocial Aspects of Cancer Experience' that needs to be addressed by *Fun with Cancer Patients*. And yet, from a critical perspective, it feels that the engagement that I've enacted with *Fun with Cancer Patients* is a direct result of the reading and consideration of practitioners and theorists like Kuppers and Thompson. Using their performance outcomes as a model, I believe that the affect created for Laura, audiences to the documentation, the *Fun with Cancer Patients* team and to myself are demonstrative of what a conscious research practice might look like. Even this uncertainty, this celebration of the end of effect — as Thompson writes — feels like an appropriate and accurate result.

The goal with *Fun with Cancer Patients* in the future is to obtain additional funding to create a total of 18 Actions and 18 pieces of documentation, which would eventually become a travelling exhibition. After 18 Actions, a rich impression of what the cancer experience looks like will be developed, thus rendering the imaginary checklist (above) unnecessary. The exhibition would pop up in a public space (without major installation or pre-exhibition marketing), much like *An Appreciation* or *Guerilla Pub Quiz* and force a conversation about cancer that was unexpected, potentially joyous, potentially difficult, but unavoidable — just like the disease itself. The metaphor of the disease is extended by the incorporation of the number 18, significant for Jews (the cultural heritage I was raised in) as a symbol for 'Life'. I don't mean to present 18 documents about survivorship or about picturing your life after illness, but I rather mean to say that cancer is a part of the process of living. It's not good, it's not bad (well, it is bad, but it's not something to judge people negatively about) it just is a part of life, at least for a huge amount of people in

the world, either affected by their own illness or by that of their loved ones. Said again, and this time purposefully avoiding the quoting of statistics: cancer is a part of life.

In January 2011, *The Guardian Weekend* featured a cover story entitled “Cancer: the new normal” with an image of a busy supermarket filled with customers who were either bald or had their heads digitally made to appear as bald. Although the cover image trades in the most typical cancer image of the bald, white patient and plays on typical cancer narratives of survivorship and stakes upped by percentages and statistics, the article (an excerpt from *The Emperor of All Maladies*) puts forward the provocative idea that cancer is a normal process, and describes how the disease is “stitched into our genetic being”.⁵¹ “The question”, Mukherjee continues, “then will not be *if* we will encounter this immortal illness in our lives, but when.” Such a statement does not fly in the face of cancer research efforts or advocacy campaigns focused at curbing exposure to known carcinogens, but does sit in stark opposition to features like ‘Picture Your Life After Cancer’ with its strong bias towards positive changes post-cancer, or Race for the Cure, or World Without Cancer, or even Barack Obama’s pledge, during his first year as President of the US, to end cancer ‘in our lifetime’. While these statements may mean to inspire research or funding for research for critical medical studies, they also increase stigma on the cancer experience. Even if a cure for cancer (an incredibly reductive term, considering the various ways in which cancer functions and appears) is found in our generations, if the focus is only on survivorship and cure, cure, cure, so much of the messy, ambiguous, difficult experiences may remain unspoken to and unspoken for. Although efforts like *Fun with Cancer Patients* do not use

⁵¹ Siddhartha Mukherjee, ‘Should we stop trying to cure cancer?’ in *Guardian Weekend*, 15 January 2011, p. 23.

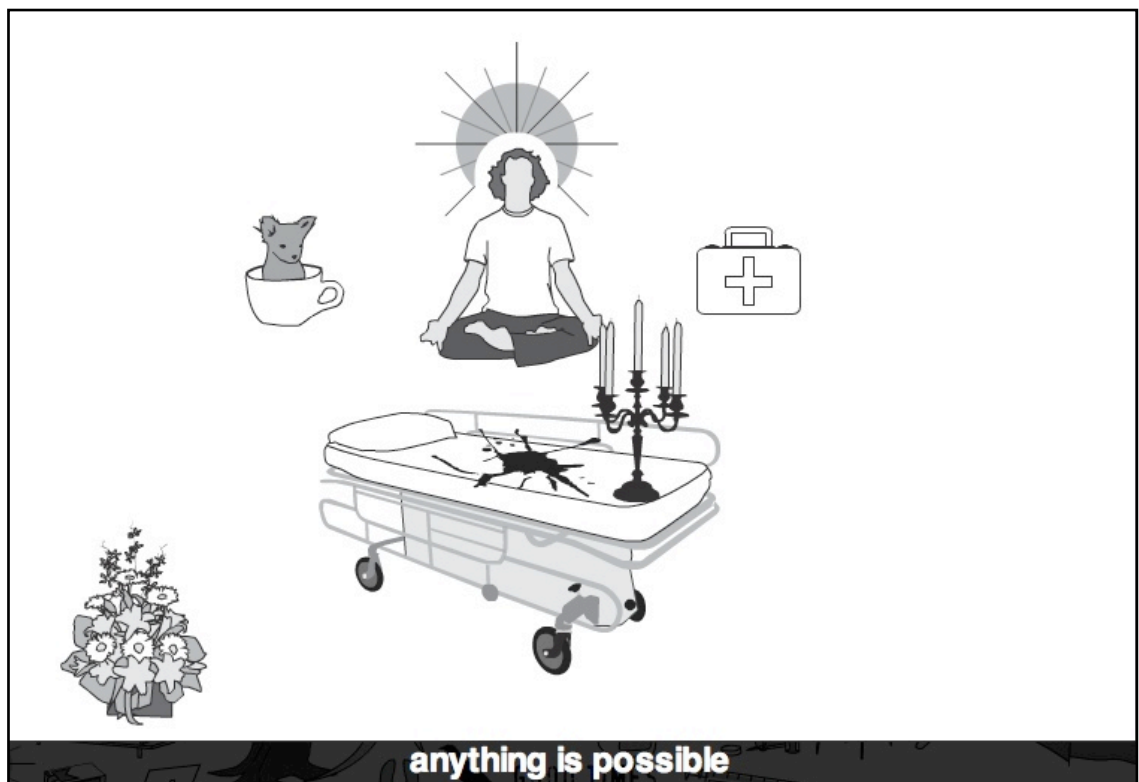
performance methodologies to cure malignant growth, it does attempt to curb the pressures that keep those with cancer from seeing honest reflections or representations of their lived experiences.

Figure 1



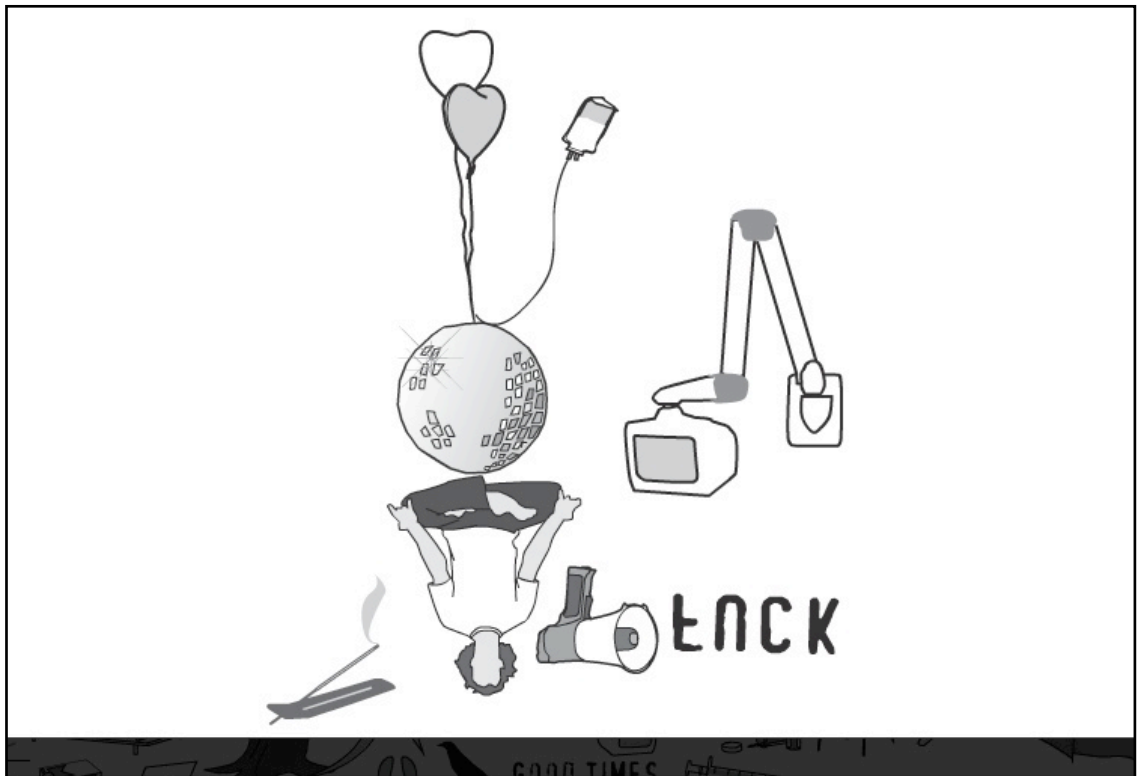
(Fun with Cancer Patients website screenshot, 2010)

Figure 2



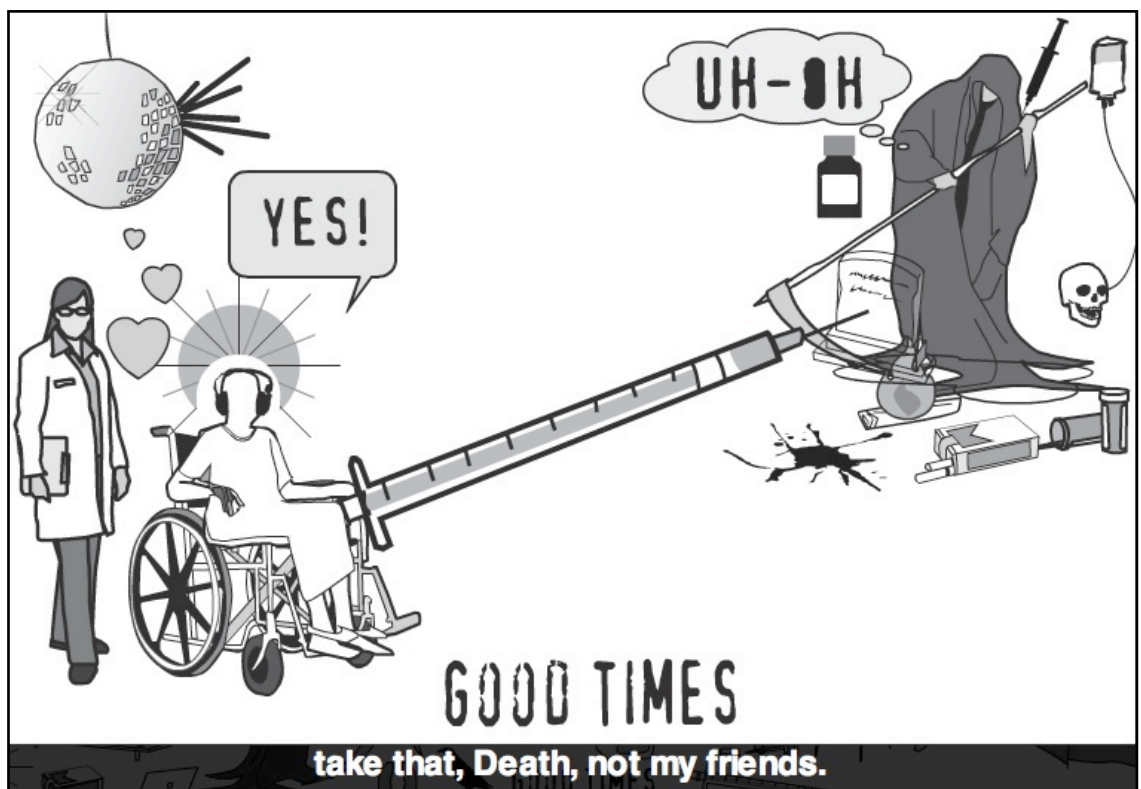
(Online Submission, Fun with Cancer Patients Canvas 1, 2010)

Figure 3



(Online Submission, *Fun with Cancer Patients Canvas 2*, 2010)

Figure 4



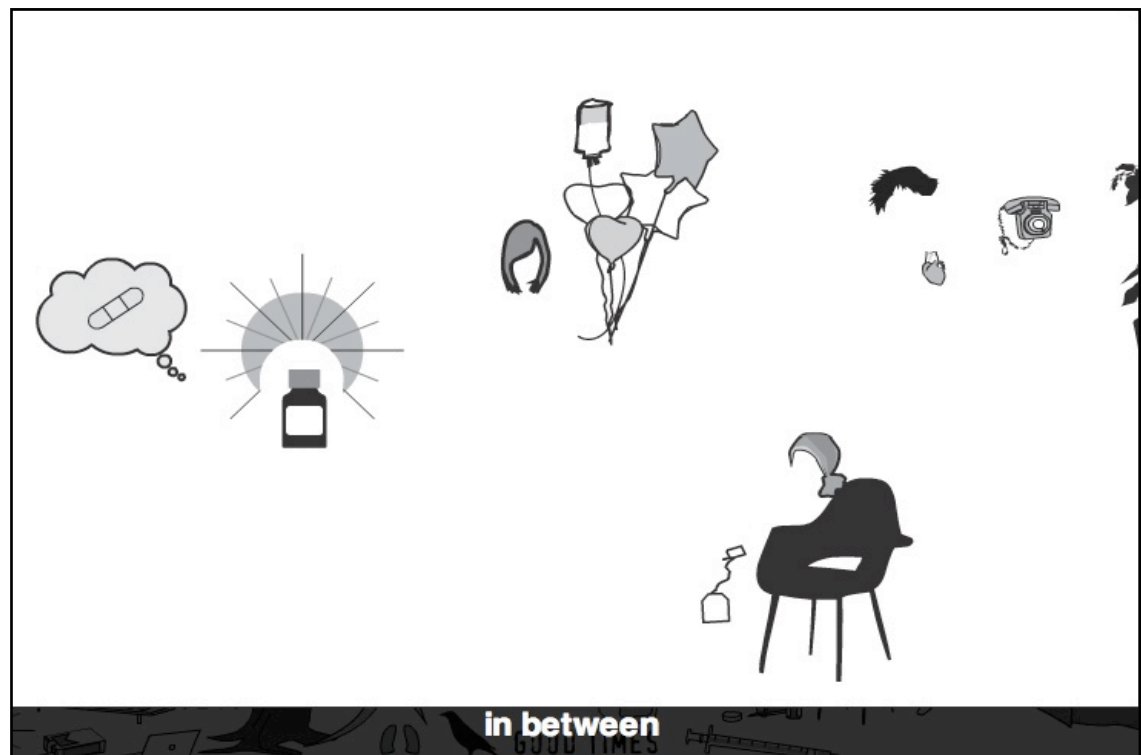
(Online Submission, *Fun with Cancer Patients Canvas 3*, 2010)

Figure 5



(Online Submission, *Fun with Cancer Patients Canvas 4*, 2010)

Figure 6



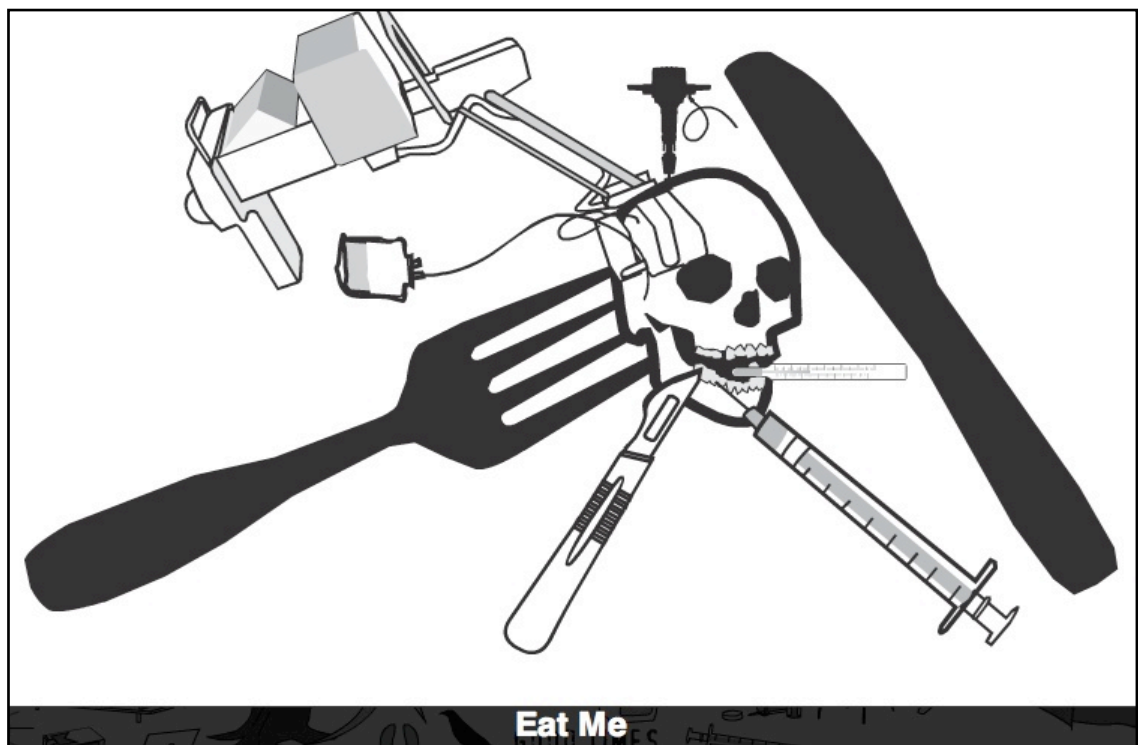
(Online Submission, *Fun with Cancer Patients Canvas 5*, 2010)

Figure 7



(Online Submission, *Fun with Cancer Patients Canvas 6*, 2010)

Figure 8



(Submitted Canvas to *Fun with Cancer Patients Website* by Laura, 2010)

Conclusion

Illness, Wellness and Performing for ‘Normals’

Theory and reflection on illness and disability do not, by any means, represent a singular or undifferentiated point of view, but they overwhelmingly take, as their starting point, an identity and point of view of non-normative experience (which, as I quote Mukherjee’s argument in the previous chapter, is really a normative experience of cancer/illness). To reiterate the work of Lennard Davis, “few ‘normal’s have resonated with people with disabilities”.¹ Until someone experiences embodied difference — either their own or a loved one’s illness — it appears as though the subjects are off-limits, or, if not off-limits, unconsidered.

Although writing from personal experience has sometimes raised critiques of people’s work being solipsistic, Audre Lorde wrote on this subject in a politically-inflected manner, saying “Sometimes we are blessed with being able to choose the time and the arena and the manner of our revolution, but more usually we must do battle wherever we are standing”.² Here, Lorde’s writing not only makes a claim for people to be engaged with work that is close to their personal perspective — even if it is an imperative, and not necessarily a personal choice — but identifies the strength that may come in such an engagement, labelling both kinds of engagement as a battle. Such a personal and powerful engagement with cancer is demonstrated by every theorist and writer I have quoted throughout this thesis, including Stacey, Frank, Sontag, and myself. Jackie Stacey highlights her experience with cancer being the catalyst

¹ Lennard J. Davis, *Bending over Backwards: Disability, Dismodernism & Other Difficult Positions* (New York and London: New York University Press), p. 4.

² Audre Lorde, *The Audre Lorde Compendium: Essays, Speeches and Journals* (Pandora: London, 1996), p. 324.

for her work with cancer, writing that her writing on cancer, much like Susan Sontag, discussed in Chapter 1, retrospectively highlighted her own experience of breast cancer as the catalyst for *Illness as Metaphor*. Even my own work about illness — both academic and performance — began only after my cancer diagnosis.

These examples of people writing from their own experience, and fighting battles³ may, however, function as one of the main reasons why the discourses around illness continue to need to be brokered between embodied experiences and discourses. There are very few case studies on how individuals create and document their experience with health (vs illness) and/or non-disability as these represent (what is currently conceived of as) normative experiences, which are rarely commented upon. This normative experience may seemingly lack the ‘extraordinary’ nature necessary to be deemed worthy about which to write, to create or even to think. While studies on whiteness and maleness and more work on heterosexuality have become critical in understanding how race and gender and sexuality are understood, similar efforts when understanding illness and the experience of non-illness (or not-seemingly-affected-yet-by-illness) have not been explored.

There have been efforts to increase consideration of disability amongst non-disabled populations, like the naming of non-disabled as temporarily able-bodied (TAB), but this is a prime example of the limitations (discussed in the Introduction) of bringing illness directly under the umbrella of disability. As a joke, if people had a hard time following information about cancer that I was discussing, I used to tell them, half-jokingly, “When you get cancer, you’ll

³ While Audre Lorde used battle metaphors extensively, Sontag famously asked for war metaphors to be given “back to the war makers” in Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Anchor Books, 1990), p. 183.

understand”. I did not say ‘if’, but rather, ‘when’. The reactions to my sentiment were always swift and often quite harsh — wood-knocking, air-spitting and aggressive glances all told me that a term like TAB could never be applied to someone who had never experienced illness, especially where the focus is still so firmly framed around getting people back to being non-ill, non-cancer patients. Language (both medical and not) is still focused primarily on survivorship or the realigning of an ill identity with non-disabled or ‘healthy’ identities.

A striking example of this “single-minded telos of cure” that Frank describes, comes with the proliferation of the term ‘Wellness’, whose history is chronicled by Ben Zimmer for *The New York Times*, which renamed its ‘Health’ column ‘Wellness’ in 2010.⁴ While often criticised by medics for its seeming-‘flakiness’, what started as a term to understand integrated medical care now seems code for the policing of terminology and attitudes around illness and disability (see *Picture Your Life* in Chapter 4). The term seems less employed as a mode of understanding wellness as representative of different kinds of experience — as Shildrick writes about disability being used strategically to describe a range of experience — and more about forcing those from unwell to well, ignoring problematic nature of the term and these efforts. To think in terms of Garland-Thomson’s stare, the current discussion of wellness no longer takes eyes off the staree, but rather heightens their glare, now policing ever more intensely. In order to stare back, the person with illness — especially if newly diagnosed and thinking about these issues for the first time — must contend with both these intensified stares from others on top of their

⁴ Arthur W. Frank, *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: The University of Chicago Press, 1995), p. 83 and Ben Zimmer, ‘On Language: Wellness’, *The New York Times*, 16 April 2010 <<http://www.nytimes.com/2010/04/18/magazine/18FOB-onlanguage-t.html?pagewanted=all>> [accessed 13 February 2012].

own radical reconfiguration of their sense of self, as described previously in Stacey. Wellness, as currently practiced and evidenced by Ehrenreich, certainly does not encourage people to think about illness or what wellness might look like in practice.

As captured by the title of Lisa Kron's performance *Well* (2007), the terminology of wellness can encourage thinking about health and wellness, conjure images of a deep, dark hole, and can also be the beginning of a pause, or a quiet, uncertain retort: 'Well...' It is this final definition of 'well' that I will explore in this conclusion, which considers two of my performances undertaken during the course of this research which, I argue, attempt to move audiences from a proclamation of 'Well' (as in 'I am well and not unwell') to a more inquisitive consideration of 'Well...', and — much like the efficacious silences of Baker, Spence and even Nicholls, demonstrate how this uncertain retort can function in brokering a conversation between those experiencing disability and illness and those for whom the realms of illness and wellness appear mutually exclusive.

In 2011, my performance installation *Carpe Minuta Prima* and performance publication *Or Else Your Friends Will Have to Do It* asked audiences to consider their own relationship with health and mortality in distinct ways. Without foregrounding issues of sympathy with individual ill bodies, I attempted to provoke what Helena Grehan describes as a 'radical unsettling' with these issues in order to unsettle my audience and encourage sustained engagement with a consideration of health and mortality. Both performances bring together many different strands of thinking present in this thesis — including, among others, remote spectatorship, potentials for silence, and translatability of embodied experience — to create audience experiences

whereby individuals can choose (or can be confronted with) an unexpected conversation about illness or, in the case of *Or Else Your Friends Will Have to Do It*, mortality. By promoting unexpected conversations around illness and mortality, *Carpe Minuta Prima* and *Or Else Your Friends* attempt to sidestep the silence or ‘dignity’ associated with illness and to promote reflection and reconsideration. This conclusion will examine how the projects’ incorporation of documentation and different modes of spectatorship solidify and sustain self-reflection about issues that many would prefer (by choice or by custom) to avoid considering. It will also consider how the physical objects, left as byproducts of performance may act as objects somewhere between *memento mori* and *memento vivere*, and consider how such items function to push forward or at least highlight contemporary fixations with illness and mortality. These objects, I argue, enact Grehan’s definition of ‘radical unsettling’ and serve as objects which nag and irritate them: “although they might attempt either to suppress these responses or to establish ways of being in the world with them, the nagging remains and demands consideration”.⁵ While Grehan used this definition to describe live performance, I will demonstrate how these objects may function as continual performances and, with their location in people’s homes, may continue to nag and irritate in useful ways — especially in keeping reflections on health and mortality never far away from everyday discourse.

Carpe Minuta Prima is a performance installation in multiple parts, each of which engaged with the locale and its population in different ways over the two-week period that it was shown in February-March 2011. In the first week of the performance, the corner of a cafe in Brixton Village Market in South London was transformed into an office which, although purposefully without strong

⁵ Helena Grehan, *Performance, Ethics and Spectatorship in a Global Age* (Basingstoke: Palgrave Macmillan, 2009), p. 7.

characterisation, played with a Mephistopholean aesthetic: blacked out walls, bright red backdrop, sleek black costumes with red shirts, and even a devil 'tattoo' on the office computer. As passersby walked through the market, they were confronted by one of five assistants, also wearing sharp black suits and red shirts. "Can I buy a minute of your time?" they would ask. Reactions were often swift, with people averting their eyes, muttering incoherently or saying "Not today" without thinking of the offer on hand. But many stayed, wanting to see how the scam would reveal itself. "I'm not sure how much you value your time for, but Brian Lobel is willing to pay you £1 for one minute of your life", the assistant would continue. It was here that the script would generally fall apart, and the audience member/passersby would ask what they had to do or what the 'catch' was, or why there was a man giving out money in a London market.

The piece took seriously its commitment to transparency, with the assistant and/or myself explaining the situation: each person would be paid £1 if they spent one minute inside a booth, by themselves, being documented doing whatever they wished. The minute, the assistant would ensure, was theirs with which to do anything they wanted — until they signed the minute over to me, after which time it would be sold to someone else for the price of £1. The contract read: "This certifies that Brian Lobel, with my consent and for the price of £1, has become the exclusive owner of the minute of my life contained within". Upon signing the contract, a photograph was taken of the individual with their coin, a testament to the fact that each participant had been paid. As they finished, I shook each person's hand, saying simply "Thank you for your time" and handed them a card saying with same phrase and inviting them to an opening for *Carpe Minuta Prima* at the end of the fortnight.

For many, their engagement stopped after receiving £1, but the performance continued. The 1-minute videos were then crafted into shrinkwrapped DVDs with the photograph of the person holding their £1 coin on front, and the signed contract on the back. A week later, at the opening, a vending machine was revealed with 320 DVDs inside, each with a picture of a person holding a single pound coin. At the opening (or what we called the Grand Unveiling), after a short speech in which I recounted minutes from the project, and gave the project's context, I deleted my all of the minutes from my hard drive, thereby ensuring that the content of these minutes was exclusively placed on the DVDs inside the machine. Each DVD therefore, became a one-of-a-kind, limited edition minute of one person's life, able to be held in a purchaser's hand, placed in their purse or backpack, or used as a coaster.

Carpe Minuta Prima responds to a number of concerns outside of health and illness — including the value of work, the gentrification of the market in which the project took place, and the racial dynamics of a white Jewish man enacting the devil, 'buying souls' in a historically black neighbourhood. However, for the purposes of this conclusion, I will consider the aspects of spectatorship and methods of documentation as they relate to a reflection on the ill body. I don't mean to devalue the other interpretations I've gestured toward, especially as they were highlighted so strongly in the piece's placement in Brixton Village Market, but the piece's origin was in response to illness and the pressure placed on people post-illness to *Carpe Diem*. In subsequent smaller touring versions of the work (at The Junction, a performance space in Cambridge, Tower Ramparts Shopping Centre in Ipswich, Jubilee Library in Brighton and Kirkgate Market in Leeds) the theme of post-illness pressure

continued to be foregrounded by both my discussions with participants and the framing of the event by the marketing and publicity.

Much like *An Appreciation*, discussed earlier, *Carpe Minuta Prima* included an unexpected moment of conversation around illness, which sought to interrupt the silence which surrounds illness. At the Grand Unveiling at Brixton Village Market on 3 March 2011 (a week after the minute-buying had concluded), the unveiling speech (quoted below) offered this context:

I created *Carpe Minuta Prima* in response to having been told, for the 9 years since finishing cancer treatment, that I am lucky to have knowledge about what is truly the value of time. I heard this from hundreds of people, most of whom seemed just uncomfortable hearing about illness, who seemed to want to justify, by any means necessary, that ‘bad things happen to good people’. “If I ever get sick” I imagine them saying, “at least I’ll learn the value of time... and then I can become a better person.”

The only thing worse than cancer, or the death of a friend, or a trauma of any sort, is to feel pressured into having that illness or difficulty necessarily be transformed into something good and happy. Many people don’t live through cancer, or suffer the death of friends without severe depression, or substance abuse, or financial hardship. Some times things just suck.

No one’s minutes need to be worth more. And a pressure to fill every second with something extraordinary seems a horrific goal. No one outside can or should determine which of your minutes should be worth more than others. That choice is yours.⁶

The ‘Context Minute’ of the speech (which was separated into five, one-minute sections entitled ‘Thank You’ ‘Context’ ‘Lessons Learned’ ‘Summation’ and ‘Deletion’) gave a clear, but brief, outline of how I view time in association with illness, especially in how I have experienced the pressure (from both other people and larger cultural narratives) to *Carpe Diem* post illness. This point is repeated in multiple narratives around cancer, but particularly present

⁶ Video available at <http://www.youtube.com/watch?v=8GTeeWtpG-E> [accessed 5 January 2012] and *Cancer Cancer Cancer Cancer: collected cancer works by Brian Lobel*.

throughout Lance Armstrong's writing, and in his celebration of the day of his cancer diagnosis, or how he calls, his *Carpe Diem Day*.⁷

The audience's behaviour after this Context Minute — as clear from their sudden silence in the video — transformed in a way very similar to with *An Appreciation*. Suddenly, this was a story about cancer. But before there was too much time dedicated to tropes of sentimentality often associated with illness, the introduction continued on, as the third minute listed the contents of some of my favourite bought minutes. This third minute was, of course, also a teaser with the goal of getting people to buy the DVDs in hopes of making back some of the pounds I had given away. Some actions in the minutes included a man singing the aria he would sing that night at the Royal Opera House; a young woman showing her portfolio and repeating her web address in hopes that the viewer would sign up to her mailing list; children dancing; a woman beating crepe batter; a man who hadn't been to Brixton since 1980 and talked about what he thought had changed. This conscientious listing of minutes, both extravagant and simple, functioned both to market the 'product' that was being sold as well as get people prepared for potential disappointment if their purchased minute was 'boring' or otherwise unremarkable. The only clue that a customer had as to the content of the minute was the picture on the front of the DVD, so perhaps they would get a Royal Opera singer, and perhaps they would watch a teenager send a text message. It also functioned to exemplify the myriad ways a minute can be 'spent'.

In the final moment of *Carpe Minuta Prima*, before the unveiling, I attempted to make sense, for both myself and the audience, exactly how the

⁷ Lance Armstrong, *It's Not About the Bike* (London: Yellow Jersey Press, 2001), p. 294.

idea of time and illness were related, and how the randomisation or unpredictable nature of the minutes on DVD might be its own content:

Some will be terrible, some will be meaningless, some will be boring, but others will be expansive, exciting, sexy, dangerous, restful, important, political, romantic or touching. Much like life. It takes all kinds, however, and, according to the clock and to the machine, they all are worth exactly the same.

By reducing the space between the holy-cancer-survivor and person-who-has-never-had-to-consider-their-mortality-or-health, this final moment heightened awareness of how language about illness (and survivorship) pervades general conversation. While the ending of my speech undoubtedly played with sentimentality, the piece's politics are genuinely and earnestly presented.

For those who have never been ill, perhaps *Carpe Minuta Prima* gets them to reconsider the judgements or expectations they place on people with cancer, or an illness of any sort, or perhaps the speech invites them to think about how they might actually want to spend their time more 'usefully', however they define this term. Even if the piece acts as a piss-take in some ways against the idea of *Carpe Diem* and the impossibility of time being more or less valuable to different people, the 'Context Minute' clearly expresses that people *can* and *should* control how they spend their time. It is only when the value of someone's time becomes a policing force from without that people, particularly those with illness, become potentially disempowered. For those who have been ill or have been affected by illness through partners, family or friends, I hope this final sentiment allows them (even for a moment) to feel free from such policing forces, as much about time as about needing to feel good about it all, or feeling that it was all 'worth it', or feeling that they are a better person because of it all. Or perhaps, again, they feel like they *do* have a richer perspective on life and its fragility and meaning, and have a more conscious approach to spending their

time. If this is the case, then perhaps the individual will realise that it was them (and not others) that was responsible for the creation of this perspective, and that it wasn't just a malignant cell that was capable of creating such profound difference in their life.

While the unexpected nature of the 'cancer conversation' in *Carpe Minuta Prima* is a strong part of its political drive to allow for critical reflection on ideas of health, the most provocative and potentially potent moment of the performance came inside the recording room, during the first part of the performance. After the contracts and procedures had been explained to the participants, I brought each participant behind the curtain into a small room (about one metre by two metres long), sheathed in black curtains, with a camera affixed to the top of the door. There was no chair and nothing to look at. The audience member would have to hit a button on the wall which would activate the lamp to flash — the signal that the video had begun filming. Before leaving the room, I reiterated that they could do whatever they wished inside the room. "It's your minute, after all, until you sign it over to me". And just before closing the door, an intentionally-difficult farewell: "All I ask is that you make it good."

"Good" for what? For whom? The question was an attempt to be purposefully obfuscating — was I asking them to make it good because they should make, as Lance Armstrong might say, Every Second Count? Or was I asking them to make it good because I was going to be reselling this minute to another person, and simply trying to protect the investment of my £1. Audience members generally understood this irony quite quickly — "What is good?" "What do you mean?" "Ahhh" were some of the most common responses I heard. But upon finishing the sentence, the door was closed and the participant was left by

themselves under a dim light. From the computer screen controlling the procedure, I could see the audience member in the small room. For most, the button was not instantly hit, thereby not starting the recording. Many would reach towards the button and then pull back their hand, or leave their hand on top of the button without starting the video. And as they did this, more seconds and minutes passed. It is this moment, the moment before one hits the button to start the minute, that I am the most interested in. It is in this moment that the person truly gets to decide, on their own, how they wish to spend this contextualised minute — whether they will seize the minute, or let it remain unremarkable.

Relating *Carpe Minuta Prima* with Garland-Thomson's writing around the stare/staree relationship, the performance specifically asks audience members to develop a strategy for how they will be in dialogue with a stare. This stare is both the stare of the camera, while also being a stare by me (watching the video production) and of the potential audience member who buys the DVD. For many, this was an uncomfortable or impossible position, but perhaps also the most affective moment, as noted by Lyn Gardner in her review of the work in *The Guardian*:

As I head to the booth to record my own minute, Lobel tells me to make it a good one. I enter with the best of intentions, but when the moment comes to press the button and activate the camera I'm lost for words. Like so many other minutes in my life, I waste it.⁸

From Gardner's video (which I cheekily bought back myself for my archive), she stares directly into the camera and tries to stay staring, but constantly looks away. Upon leaving the booth, she apologised to me about how horrible the

⁸ Lyn Gardner, 'One moment, please...' *The Guardian*, 25 February 2011, <<http://www.guardian.co.uk/stage/theatreblog/2011/feb/25/brian-lobel-sell-minute-of-life>> [accessed 4 July 2012].

minute was, and about how she tried but how she just couldn't look at the camera for too long. While Koppers has talked about disability in relationship not to staring or gazing, but rather to surveillance (discussed in Chapter 2) perhaps *Carpe Minuta Prima* demonstrates a moment of interaction with surveillance in a manner which is similar to the stare, albeit this time employing a video camera not unlike CCTV.

For many audience members who participate in *Carpe Minuta Prima*, they may not relate one shred of this experience to a meditation on illness, particularly because illness is not brought up literally, nor are their bald heads or tearful music. While these participants may have been confronted with a conversation of illness if they attended the unveiling the following week, a smaller number than 320 (the number who sold me their time) attended the 3 March unveiling than did the week-long installation. If their interaction did not inspire a sense of unsettling around illness or even about gentrification or the worth of our time, perhaps it got them thinking about what to do with their extra £1 or how their average day was disrupted by a live art performance. Additionally, considering the affect of the performance, the fact that many (particularly the younger audiences who attended *Carpe*) did not consider the value of their time, or how they must spend their time, may be demonstrative of the work as a metaphor for how some people remain unaffected by illness, or thoughts of illness. Perhaps they'll understand the value of a minute more clearly, as I've said before, *when* they get cancer. Or, maybe, they already have considered their time by rejecting the offer to be a part of my performance, valuing themselves at higher than £1 per minute. This issue wraps around to the beginning of this conclusion: if *Carpe Minuta Prima* doesn't interrupt the reality that people only write or think about illness after it personally affects

them, it presents itself as an artistic response to this issue. Although individual audience members were never interviewed as to why or why not they participated in the performance, I hope that the needling of the process of reflection demonstrates a movement forward in the thinking about illness and wellness.

When *Carpe Minuta Prima* was over, the audience member was potentially left with three physical objects, a business card (thanking them for their time), a £1 coin, and/or a DVD of one minute of the life of a person — perhaps a stranger's, perhaps theirs, or perhaps someone they've seen in the market before. These objects continue to disturb the drive towards complacency or cultural bias against a consideration of death and illness, which as Walsh writes, have "no place in public life".⁹ The objects, however, place the public performances into people's private lives. While I don't have high-hopes for the business card to be a consistent reminder of the project, perhaps it gets filed in someone's drawer to be found at a later date or tacked up (as my friend Cassandra has done on her mirror) as a reminder of the project. With the coins, my greatest hope is that people will look into their wallet or change purse and not be able to identify which £1 was from the project and which was just random change. It is here that a reconsideration of value and our time may be present, perhaps it could be put towards a coffee, or saved in a box (as a young boy said he would do), or used to buy a copy of the *Big Issue*. Many people (approximately one in five) asked where they could donate the £1. They were disturbed when my assistants and I insisted that they could not give the money back. This, like my performances of *BALL* before, is not a fundraiser, I would say, and I would encourage them to come back the following week and buy a

⁹ Fintan Walsh, 'Between Deaths: Screening Jade Goody', *Contemporary Theatre Review*, 19, 3, 2009, p. 384.

DVD or to spend it wisely. It was after this exchange that people looked the most shaken. While £1 can buy very little in Brixton Village Market, or anywhere else in the UK, to be given cash from a stranger was an opportunity few seemingly experienced. As Rita Marcalo received outrage over the expenditures of *Involuntary Dances* (as being seen as taking *from* people with epilepsy), audiences seemed disturbed to receive money as part of a not-for-profit performance. Although I believe that only rarely do people look at a £1 coin and say “I must do something *GOOD* with this coin”, the performance (or the not-for-profit, or reflective space) around this coin imbued the object with a specific meaning and documented a specific experience or time.

Each of the 320 DVDs was professionally shrink-wrapped with a label placed on the outside reading *CARPE MINUTA PRIMA* and my signature. The goal of this arrangement (label stuck onto the outside of the shrink-wrap) was to cause audience members to pause before opening the DVD. If they opened it, it would no longer be a mint-condition art object as the wrapping would look shoddy and the DVD case otherwise unadorned. But without opening it, they could not know what the minute held. While many audience members quickly ripped into their DVDs (some bringing laptops to the opening event so that they could watch them instantly), others told me that they had kept them on their desk and never intended to open them. When pressed as to why they hadn't, one man, Marcus, told me that he didn't want to 'ruin it'.

With this open-it/don't-open-it dilemma, or moment of indecision, I hope *Carpe* opens up thoughts about experience, sympathy and empathy. Without opening the DVD, the person can never know what is on it. They can think they do — they've seen the picture on the front, or might even ask the person (if they could find them) what they did during their minute — but they would never really

know. As Schneider wrote about Civil War reenactments, discussed in the Introduction, by *not* witnessing the event itself (the audience members were seated on bleachers outside where the reenactment was taking place), spectators like Schneider were forced to wonder, even more than at a traditional ‘show’, what it was they witnessed, what it consisted of, and how their distance from the (live and historical) event affected their understanding.¹⁰ This questioning, I argue, forces spectators to be ‘nagged’ or ‘irritated’ by their lack of knowledge, forcing them to ask questions, to talk about the experience from a perspective that they know — probably employing various clichés, sentimental tropes or other culturally-learned behaviour — or to withdraw from the conversation altogether. If spectators to an historical reenactment, or to an illness, find their lack of connection with the subject at hand (the Civil War or the Civil War reenactment), they may find that it is the last time they willingly attend such an event. Although historical reenactments of battles are, presumably, voluntary activities, illness — as described throughout this thesis — is not. This research thus adds a new distinct feature — imperative — to Schneider’s discussion of historical reenactments and our distance from the live event. *Carpe* asks audiences to force themselves to experience a distancing in a manner which, I hope, enacts a metaphor for the experience of illness and how that others serve as spectators to that illness.

Because I’m skeptical about performers making overly-ambitious claims about their own projects, I give myself pause here before making too-extravagant claims about the power of *Carpe Minuta Prima* to draw a metaphor for illness (and cancer specifically) and how it can be communicated to those who have not experienced it, especially because the piece consciously didn’t

¹⁰ Rebecca Schneider, *Performance Remains: Art and War in Times of Theatrical Reenactment* (New York and London: Routledge, 2011), p. 33.

force a conversation about the content onto its participants. Without opening the DVD oneself, however, a person couldn't know what was on it, and they couldn't ask anyone what was on it because no other copies existed. And even if they found the individual who performed in the minute, they would only be able to explain it from their point of view, and not from the camera's. Even if I'm uncomfortable making such bold claims that everyone thought through the previous metaphor fully, I do believe that many conversations and reflections were started by the work. For the participant, it is the presence of this object in their home — wrapped or unwrapped — that I hope motions towards a consideration that lasts longer than the five minutes in the Brixton Village Market having their minute bought, or at the vending machine where they chose which DVD to buy. The objects and mementos act like scars, ideally interrupting people's lives in sometimes simple, and sometimes more dramatic ways, reminding them of their deal with the 'devil', or in this case 'the performance artist'.

The objects survive as *memento mori* and can be playful, weird and uncomfortable — much like the classic paintings of *memento mori* which included skulls, amulets and locks of hair. In 2010, *Performance Research* published a Special Issue on *memento mori* and the performativity of objects which may relate to mortality. Of particular interest to my project is Natasha Lushetich's study of T. R. Ericksson's *All Will Be Well*, a glass urn, part of the Progressive Corporation's visual art collection, which contained the human breath of one of its deceased employees.¹¹ The majority of Lushetich's examination considers the glass urn as raising a number of issues related to Progressive's sense of community from a business perspective. For me,

¹¹ Natasha Lushetich, 'On the Performativity of Absence: Death as community', *Performance Research*, 15, 1, 2010, pp. 81-89.

though, the most striking aspect of the research comes when thinking of a corporate office holding a reminder of one of its deceased employees (or of mortality) as a permanent fixture. Quoting Jean-Luc Nancy's *The Inoperative Community* (1991), Lushetich writes, "in presenting the viewer with a temporarily extended 'trepidation on the edge of being', it communicates the immense vulnerability a singular mortal being feels in the face of finitude".¹² The vulnerability of the image in *Carpe Minuta Prima*, not necessarily experienced as vulnerable by individuals when having their picture taken, was ably translated to the audience when the vending machine was revealed: suddenly, 320 faces — similarly holding up a £1 coin — appeared strangely frozen in this space between their life and the documentation of their life. Reiterating Sontag's work on photography: Precisely by slicing out this moment [of a photograph] and freezing it, all photographs testify to time's relentless melt".¹³ The image of the participant was never meant to be happy or without pain as it was meant to signify the capture of someone's experience in a strange kind of mugshot. Although the capture was consensual (as proven by the contract on the back) it was aestheticised, and for their personal profit, even if the person had wished to give the £1 back. The goal of *Carpe* was to create an object which could sit in someone's home that unsettled their DVD or CD collection and ideally encourage them to show off the minute (of someone else's life) that they owned, or place it in a special location. While differently inflected than Ericksson's glass urn with a dead man's breath, the image on the front of the *Carpe* DVD brings a similar feeling of captivity and preservation of a thing (a piece of a life) which cannot usually be captured or preserved.

¹² Lushetich, p. 89 and Jean-Luc Nancy, *The Inoperative Community*, trans. Peter Connor (Minneapolis and London: University of Minnesota Press), p. xviii.

¹³ Susan Sontag, *On Photography* (New York: Farrar, Straus and Giroux, 1977), p. 15.

Or Else Your Friends Will Have to Do It

Disturbing someone's DVD or CD collection in a way which was connected to mortality, in a manner similar to Ericksson's urn, was an essential element of my project *Or Else Your Friends Will Have to Do It*, which was piloted at the Forest Fringe in Edinburgh in August 2010, and premiered at Chelsea Theatre's Sacred Festival of Live Art in November 2011. Subtitled "A One-on-One Performance for You and Your Music Collection", the performance is a publication, delivered to a person's home and read in their own time and space. The publication — an envelope including a small packet filled with 50 small notecards, a blank CD, a pen, a label and postage — describes the process by which I chose songs to put on the mix CD for Grant's funeral, a job I was given to coordinate in February 2010. The job was, beyond a doubt, the most intimidating and frightening experience I've ever encountered as Grant had made mixes religiously while he was alive and felt very seriously about music. To honour him with the correct mix seemed like a gigantic and incredibly intimate task.

While the text of *Or Else Your Friends* attempts moments of lightness inside otherwise difficult emotional material, and recognises the inherent resistance which might accompany a person's interaction with such a story, the publication slowly morphs into an instruction book, and asks audience members to create their own mix CD for their own funeral. After the mix is created, the text then asks the reader to identify someone to whom to send the mix, in hopes that they have it should anything happen to the audience member. The title, I hope, begins to take on a more clear meaning after this context becomes clear: *Or Else Your Friends Will Have to Do It*. The text repeats "This

is not morbid, or it is not intended to be” throughout the performance, but I know (from the pilots and from my own reactions) that the act — if audiences choose to complete it — can tread on quite difficult emotional terrain.

At the end of the performance, one of two objects remains: the first is the mix CD at the home of the audience member’s friend, who received a nondescript package with a letter explaining the project and the CD, and the second is the CD, the instruction book, and the packaging, either completed but never sent or never completed altogether. In both cases, the objects serve to create an ambivalence about issues of life and mortality in an unexpected place. Perhaps the objects will be stored, but, unless thrown away completely, these documents will remain in the audience member’s home, asking them to reflect on mortality — their mortality or the mortality of their loved ones — through objects that would otherwise hold no sentimental or particularly rich history. A mix CD between friends would otherwise just be a mix CD, a DVD of a recording of a minute of someone’s life is just a home video.

Carpe Minuta Prima and *Or Else Your Friends Will Have to Do It* attempt to create a space for reflection, reflection about issues which people would prefer not to think about, or would prefer to think about in a tone which they are conditioned to believe is the ‘appropriate’ or ‘dignified’ tone about which to consider these issues. By the time people think about them, it’s probably because it’s too late, and their life is seemingly- or irreparably-altered. By promoting consideration of these themes before a cancer diagnosis or emergency of some sort, audiences can develop faculties for understanding these potentially-traumatising frames when confronted with their presence in their individual lives and bodily experiences. Instead of causing an ambivalence, or nagging, as Grehan describes, perhaps it is more accurate to

frame the work through Thompson's term *difficultness*, which "implies incompleteness: an avoidance of neat resolutions or linear accounts of history that end in a happy present that has resolved the dangers of the past".¹⁴ Instead of, as nagging might suggest, disturbing sensibilities, as Grehan describes, Thompson's *difficultness* implies that the disturbance is an important part of a life journey, not impossible to overcome, but difficult, and which leaves open the value ascribed to besting or beating that difficult time. It's not heroics to move beyond difficulty, nor is a happy or resolved ending guaranteed: it is all just part of the trajectory. By recognising illness, this liminal space which all sojourn throughout their lives, as a *difficultness* (as open as that term suggests), perhaps the experience can be less about having others force people into wellness and more about having them recognise the *difficultness* itself and accept that this is a place where, sometimes, bodies are meant to be and where they themselves, will someday find themselves.

This thesis has argued against the pursuit of neatness, like Thompson quoted above, and perhaps even embraced Kupperts' idea of unknowability which I rejected at the beginning of this research. As each chapter, I hope, has demonstrated, by thinking more concretely about how people are acting as spectators to the illnesses of others, and being conscious of how they are the objects of spectatorship during their own illnesses, it is possible to push conversations around illness out of medical determinedness into a space of more productive questioning and constant reconfigurations. The constant reconfigurations between starrer/staree, spectator/spectated may not cure disease, but may ably inspire people with illness to feel more empowered in the process of determining their relationship to the outside world and to develop

¹⁴ James Thompson, *Performance Affects: Applied Theatre and the End of Effect* (Basingstoke: Palgrave Macmillan, 2009), p. 80.

strategies — espoused by Garland-Thomson and demonstrated by Nicholls, Hallenga and Kilburn’s blogs — to stare back. It may allow them to take time for non-production, as demonstrated in the work of Spence, Baker and Sontag in Chapter 1, or to allow their silence to be productive and strategic. They may also choose to produce work that may not conform to expectations, as demonstrated in the work of Flanagan, Marcalo or Baker. The lens may also allow people to craft their own narratives from their experience as opposed to relying on those stories already provided for them, as was evidenced by Nicholl’s blog in Chapter 3, and, I hope, by the work of *Fun with Cancer Patients* in Chapter 4. Most importantly, however, the research attempts to shade the area between the ill and the ‘outside world’ not only because such a distinction is unhelpful, but because it is unrealistic. Instead of seeing oneself as disconnected to the world during a time of illness, it is the goal of this research that the experience of illness gets recouped as a normative experience. The first step in this process, I believe, is by demonstrating — as I hope I have done here — that each person is capable of being both starrer and staree and the carer and the cared for, the reality of which provides complicating depth to the enactment of these various roles and the times of their different iterations.

Confessions and Conclusions

In a passage from Lucy Grealy’s essay ‘Mirrorings’ which was the source material for her book *Autobiography of a Face*, she describes how one day, after seeing the man from the corner store, and constantly waiting for him to ask about what was ‘wrong’ with her face, she writes that she couldn’t stand the polite silence any longer:

I blurted out my whole life story to the man behind the counter. I was holding a glass bottle of milk, letting the whole saga stream

out of me, when the bells tied to the door jangled. A man completely, and I mean completely, covered in tattoos walked in. I stopped midsentence and stared at him.¹⁵

This passage, more than any in Grealy's writing, highlights the colliding of individual, isolated experiences. For years, Grealy felt like the only one who was stared at, a reality which becomes all the more potent when, in a moment of vulnerability, Grealy becomes the staree. It's messy and multilayered and presents a deeply ambivalent and difficult statement of our unknowable individuality and our ability and our want to know others.

In Chicago, in August 2011, I went to the Alliance Bakery in the Ukrainian Village to attempt to give this thesis a satisfying bookend about growth, temporality and how the body changes over time, thinking that my body no longer remembered the sadness that it had 16 months prior in relation to Grant's death. I sat on the porch before going in, taking notes and feeling, well, nothing. The place didn't have a meaning on that day, it was just a coffee shop. So I would write about the passage of time and how experience changes, as my body had changed through *BALL, Other Funny Stories About Cancer* and *An Appreciation*, and how one day I'd be able to reflect with distance on my grief from 2010. I would not use the term difficultness or nagging, as I didn't quite feel them, but would rather use the word *linger*, as used by Thompson elsewhere, that implies a more passive, perhaps quiet, interface with past memories and images.¹⁶ As lingering feels critical because it demonstrates that an event is not just a time-bound phenomenon, I would feel like this relationship to my history was a mostly-passive one: informed, yes, but perhaps not under its absolute rule.

¹⁵ Lucy Grealy, 'Mirrorings' in *As Seen on TV* (New York and London: Bloomsbury, 2000), p. 42.

¹⁶ Thompson, p. 157.

I walked in, just to buy a coffee, and then I heard it: ‘Chicago’ by Sufjan Stevens. The first song on Grant’s funeral mix. “I fell in love again/All things go/ All things go...” Breath escaped. My hands literally shook. “Are you ok?” the woman behind the counter asked. “Yes, I’m, yes, this song...” “Yeah”, she responded, “It is definitely that kind of song... I’m hoping it’s good things that it makes you think?” I wanted to lie and not overburden a stranger behind the counter. I wanted to make her think that it was from a romantic evening, or my first love, not that it was from a funeral mix I created, which was the subject of my research, which I had come to write the ending of. But I couldn’t lie and, like Grealy, blurted the entire story, in what was, I’m sure, one of the most publicly emotional she had seen at her bakery. The relationship, the death, the return, the research, the performance, the song, all of it, it just came stumbling out. With compassionate eyes she held my stare and I was unsure if I was staring at her or she at me. In that moment, I couldn’t know if the relationship between starrer/ staree was reciprocal, as Garland-Thomson writes, or if it was something invasive, exoticising or needy. Maybe she had a similar story and would tell me, or maybe I was just acting crazy. Either way, I wouldn’t know, as her co-worker walked in from the kitchen and I quietly excused myself. “Anyway, I should...” Her “Thank You” was pitched just above the normal customer service tone, but revealed little. In that moment, I didn’t want or need her to have experienced the same thing — and I hope she hadn’t — but I just needed her to be witness to that story, in that space, long after the song had since ended. After all of this theorising and thinking, I still wish I knew why.

Sifting through the pile of documents that I have considered throughout this thesis, I am overwhelmed by how experience is marked, made tangible, kept, archived and remembered. People have looked to letters, oral history and

photographs in the past to document experience and remember what came before, and now I find myself expanding on this, adding memories of gigs and performances, videos of work, reviews by academics, tagged Facebook pictures, transcribed interviews with colleagues, blogs of cancer patients, iTunes playlists, and even the scars on my own body — those from cancer surgeries and those I gave myself in remembrance of Grant — to access ghosts and stories. These documents, these things that are left, provide moments that pierce, heighten and remind audiences of their own mortality and their own relationship to mortality. Performance, and a consideration of how we become spectators to our own life, especially, but not exclusively, in the face of illness, can provide a lens to see how we watch these documents, how we access them, and how they make us feel. Sometimes these documents can make us feel sad, sometimes enthusiastic, sometimes deeply ambivalent, and still processing those difficult and extraordinary events which came before and will, inevitably, come again.

Appendix A

Interview with Rita Marcalo

Ilkley, 5 April 2010

Rita Marcalo: So the project... I've always thought that one day I would like to explore my epilepsy through my work, my performance, but I was waiting for the right time. In 2007, I was offered an InterAct Award which meant that I could do a four month residency at GlaxoSmithKline down in London. One of the things they produce there is anti-convulsive medication. They just research it there. So I was talking to biologists, biochemists and neuroscientists. After that research period, I spent a lot of time just reading about epilepsy from a scientific point of view and the drugs point of view. And then I decided I wanted to go and make this work. Its a trilogy of works that I'm doing — the first one is the one you've probably heard about, *Involuntary Dances*, which looks at all the behaviours in my daily life that I avoid in order to keep my body out of the convulsing stage. So all the things I do not do, all the prohibitions. And it looks at, actually, for the period of 24 hours, breaking all of those rules and doing all of those things and finding out how much I would have to push my body for a seizure to happen.

The second work, which I'm touring at the moment, called *She's Lost Control*, turns it the other way around. This piece looks at all the control behaviours that I engage with in order to avoid that — checking my temperature — the other side, trying not to...

The third piece that I hope to look at next year, actually just looks at the drug, this medicine, this compound, this chemical thing that I take twice a day and millions of people throughout the world take, that enables me to live my life without this body. And the thing that I'm interested in — I don't so much look at it as an illness... the reason why I got really interested in this is because being a dance person, being a body person... I've always felt that there are two states of me — two states of my body. One is this one and the other one is this other bodiless state. There are two sides of me. I know that it is culturally or chemically constructed as an illness, but I was trying to explore it in this way.

Brian Lobel: And I'm sorry if I used the term illness...

RM: No, no, no, discourses around what illness is is of course what I'm trying to explore.

BL: You say this very eloquently in your artist statement. If it's ok to talk about *Involuntary Dances* first and then move to more general things. How did Bradford Playhouse connection come about...

RM: I approached them. After having approached another organisation with whom I've worked and have a long standing relationship — I've performed in this other place loads of times — and I approached them with this piece and I was stepping out of my practice quite a lot and for them, it was a step too far, and for them, they couldn't engage with it.

I performed at Bradford Playhouse before as well, a few times. I knew that they had changed from whatever they were before. When I performed there, it was still there... so kitsch. But anyway, I knew they had changed, they had new management, they were a group of young people running it as a collective. And I think that was what interested me. I rung up and I first talked to Ade — who was like 'Yeah, we want it...' and their attitude to it was so unlike everyone else. They were just like 'Great, we'll make it happen. I don't know what's going to happen, but we'll make it happen.'

Eleanor's amazing. She is probably one of the few people in the country that she could take that show.

BL: And how was that relationship in preparation...

RM: It was great, it felt like the whole time we were negotiating, because no one really knew what it was going to be and where it was going to happen, and how and in what format. And it felt like a collaboration. And Eleanor, and everyone at the Playhouse, they were so generous, not only with ideas, but with their contacts, and just saying 'We'll make it happen'. It felt very good. So from my team, there was me, and Jim, who was working as a Production Manager, and my manager, Eleanor and all the other staff. The whole thing felt like it developed in an organic way. Some of the things we did were Eleanor's ideas, like the live link.

BL: And the world went crazy. Before we get to that... Had you previously done conscious literal work with people working with epilepsy outside of GlaxoSmithKline, because there are these large online communities, organisations, but you hadn't interacted with them before.

RM: No. This for me was... If I'm completely completely honest, it was so personal... I'm going to liken it to a coming out — like a sexual orientation coming out. Up until then, I felt like — one, I felt like I didn't have the right to call myself a disabled person because my epilepsy is for the most time controlled. It didn't feel like my identity. Even though I have all these things that I'm entitled to because I'm disabled... And so, for me, it was almost like... I had to wait until now, to kind of deal with that now. Throughout my life, I was very careful when I disclose and to whom I disclose about how I have epilepsy. My seizures are always kept — I always tried to have them in the toilet, away from everyone else. It was almost like a coming out — it was almost like "Look, I have epilepsy and here it is, and I'm exposing it." And so, that's why until then I hadn't engaged with any organisations because I wasn't there, with myself. I was just getting there, through the work.

BL: Idea of passing... When the reaction came... How did that come to you??

RM: I was prepared. I knew just from understanding how things work — I knew that this work would cause a certain amount of reaction — but I honestly thought it would be a local thing. It might be in Leeds or in Yorkshire — in the Yorkshire Post. But that's it. But I was actually in Lithuania on a job when I got a phone call on my mobile — which is my work mobile and is on the internet. I got a phone call from *The Independent* asking me some questions about my work... and I go "Oh, ok, I'll give a little phone interview"... And right at the end, they asked "And how do you respond to the criticism..." "What criticism?" I had been in Lithuania — no computer access, nothing. I put the phone down and I went to my hotel, asked for the computer, googled myself and almost had a heart attack. I wasn't expecting that. I wasn't expecting that! I still... I understand... Now I understand much more, what I was playing with — which is the — it's the idea of exposing this grotesque body — this not normative body as you say — actually it's so not normative that causes this reaction... But like everything — when it's close to you and you've lived with it for a long time, you kind of lose perspective on the cultural pressures which try to keep that body out of view. This just made me more intent on showing it.

BL: Everything from Bradford Playhouse sounded really supportive...

RM: The arts organisations were extremely supportive — because they understood it as a piece of art which a lot of the media that were writing about it did not.

BL: Did you ever have face-to-face or email exchange with the Epilepsy Action...

RM: They wrote to me, I didn't answer back. I didn't think it was useful. I might still one day do it but if I do it I will do it as part of a work or in some other form. A lot of people wrote to me. A lot of people with epilepsy wrote to me, very angry. A lot of people who have lost family members to epilepsy wrote to me, very angry. And the charities of course were very angry. Epilepsy Action wrote to me, not so much angry, just concerned — this old idea that epilepsy charities have that you shouldn't expose disability in any way that is funny or outrageous because it goes back to the freak shows because a lot of people with disabilities these days... There is kind of a sense that you are reclaiming the freak show in some sense. They were concerned about that. They said that I was taking back years of education in terms of disability. Taking us back to the Victorian ages...

BL: That just hardened your resolve?

RM: Yes, that was exactly one of the things I'm playing with — it's not that I don't understand that. The whole thing about voyeurism — what I'm interested in doing is disrupting something from within. By creating something which exposes the voyeuristic natures of it, you are almost deconstructing something but from within. You can explain that to an artist or to a person who understands art theory but it's hard to explain that to an epilepsy charity.

BL: [Talks about Bobby Baker and her relationship with the Wellcome Collection's marketing department — which attempted to control the tenor of her show]. Did you follow a lot of the online conversation...

RM: I did at the beginning but then I stopped. After a while it wasn't useful. Also I was dealing with so much. There was even this shadow arts minister — asking for the work to be stopped. There was so much pressure for it not to happen that I have to admit, I went into 'Make it Happen' overdrive. I was so busy and so tired by the end of it. And it's only now, actually, after the work is finished — it's only now that I'm starting to process things and beginning to process what happened and the work. Not so much as what happened in those 24 hours at Bradford Playhouse but the discourse that it produced and seeing this as the work as well.

BL: This minister, this involvement — I didn't think about this today when I was re-reading... So much of this conversation was about money —

RM: Typical *Daily Mail* headline...

BL: What this woman is doing with our money. It's just increasing unpleasant... how bodies are policed: women's bodies, disabled bodies, bodies with illness... it's typical, just unpleasant. The propriety of 'Let's protect this woman from herself' was actually about 'We shouldn't have any arts funding because of this woman'. Next question: You weren't really before engaged with disability work — is it now something, once out, is it something you are more comfortable with — are you engaging consciously with it?

RM: At the moment, one of the good things that happened, I got approached by a lot of people and started talked to a lot of people who are involved in disability arts movement and signed up to a few newsletters, started reading about it... and I feel more — well, I'm out as a disabled woman which is good and I'm really really happy about that. And it feels like when I came out as a lesbian. I'm out to everyone who knows me as a disabled woman. And I feel like I can claim my word for myself and not feel guilty. My whole guilt trip was "I'm not that... I don't really deserve it." And now I'm engaging with the politics in a different way.

BL: Presumably not with Epilepsy Action.

RM: No, no, not really. [laughter]

BL: Were there people within epilepsy work that you found supportive?

RM: No... Actually... I'm very disappointed in the people that I was working with — particularly with epilepsy, which were a group of neuroscientists. Because of the media frenzy, they just left the project. They were attached to universities and all the universities just got scared and they left. I'm trying to find... I've just applied to another thing in the States so I can work with a scientist or a neuroscientist... So that was the disappointing thing.

BL: I'm sorry to hear that. Is there anything else about experience I forgot to ask you. I thought so much about it was interesting — I mean the message boards themselves...

RM: Yes, oh this is something I must write about. One of the thoughts that I must write about someday... How interesting it is that it was a work that was so talked about and actually only a few people saw — the audience was minimal. And what I found interesting... someone wrote that "I'm going to be there, I'm going to see it" and someone wrote "What kind of sick person are you?" so there was, on a virtual level — people making judgements on people who said they might see it and who ended up not seeing it. They ended up not seeing it. Just the thought of it generated all this. People also said "I can't, I'm not going to go because I can't cope with seeing you..." A lot of people stayed away from it — the thought of seeing it was too much. It was only 40 people.

BL: And I think about myself and if I would have seen it. I think it would have been helpful — I saw three seizures when I was a young child, and it would be really nice to see one in a controlled environment.

RM: I wanted to say "Come in and stare, please do. Pay for a ticket and pay for the freak show". I'm making the offer and so you can feel ok with starting. I was making it happen.

BL: I was wondering about your work and the relationship between advocacy and spokesperson-ship... This was framed around not only you but about epilepsy and bodily control more generally. That feels like a tension that existed in the conversation.

RM: One of the things that I said at one point was, at one point, in some interview, I said something about raising awareness — and that just got taken and repeated all sorts of times. And halfway through the process of being repeated and repeated it became something I never meant it to be — but it just became it. When I spoke about raising awareness, I was talking about — of course it's not just about me, but it came from a personal point of view. It came from the point of view as a person with epilepsy looking at notions of voyeurism in our culture looking at this idea that you're not allowed to see, you want to see, everybody wants to see. Looking at control, looking at behaviours. And also looking at the idea that someone with epilepsy is somebody that can be intellectual, can be a performer... But once the notion of raising awareness got commented on by epilepsy charities, it became a different thing, which wasn't necessarily what I had intended. So when I was talking about awareness, I was talking about a cultural commentary point of view, as an artist that's what I do... but then it became this other thing.

BL: You were, to them, they thought you were encroaching on their territory. Because your work was never framed around that — you didn't send a press release to the Epilepsy Action...

RM: It wasn't linked...

BL: Raising awareness was the cultural comment...

RM: Once it started getting used in that way and then the epilepsy charities commented 'This isn't the way of raising awareness' because raising awareness for them is a different thing... Then I got a bit — Oh god — That wasn't really ever what I intended anyway.

BL: It's hard to say "I don't want to raise awareness" about something.

RM: Can I say one more thing... now that you mention marketing... and when you mentioned Bobby Baker's tensions with marketing. The first marketing press release I sent out... because I wanted the playfulness of the piece — which is about a serious thing, yes — there is like a one in a million chance that I could die... let's not even go there. I wanted it to be witty and playful. The first press release that I sent out said 1/4 pyjama party, "Come to this event it's 1/2 pyjama party, 1/2 voyeuristic pleasure" I can't remember, but it was something that was along those lines. After the whole media thing, the CIDA — Cultural Industries Development Agency — very kindly paid for this p.r. person to work with me because they thought I needed someone to help me manage it. So this guy worked with me and the first thing he did was cut this out and I thought "Well, Why, this makes it playful and light!" And he said, "It's inflammatory. It's inflammatory because you are playing with something that everyone thinks is very serious", and we did have this discussion and in the end I did acquiesce. And I think it did take away from how I wanted the event to be sold. I think in the end I did acquiesce because initially I had it that this press release would go around the art circuit — and people understand this kind of play — and then I had to consider this other audience. And he said "Whether you like it or not, you have to engage with the *Daily Mail*" and I said "NO" and he said, "Well it's already there..." which I wasn't pleased about, but anyway...

BL: Something that Jo Verrent wrote about... One of the terms she used 'The Disability Rulebook'. "You should only produce work that relates to your work in accordance with the social model of disability, and not show anything that shows fatigue or pain..." You didn't know 'The Disability Rulebook' existed...

RM: There was definitely that. Obviously as someone who has been involved in community arts practice I was aware of the debates around the social model of disability versus the medical model, but I hadn't thought about how this work was going to fit in with it or not. This is something I was going to do, and it was only after... because I wasn't there as a disabled person, this was on my way in... it was the exposure of it, and the dealing with it at the same time. I suppose what I am trying to say is that I was aware of them but I hadn't located myself in them [the discourses].

BL: What I'm interested in, eventually down the line, is people creating work in response to an audience that might not exist, but is judging and policing...

RM: In a way, I'm glad that I wasn't so aware of those things when I made the work — I might have censored myself in ways that I didn't.

BL: I think the final chunky issue, is the idea of solo performance, wondering if it is or isn't a natural space for being an advocate for something. Because of the I in front of

others. So much of the time, on the message boards, people kept writing “I know and she doesn’t know.” “I am the authority and mine is more serious than hers.” I was seeing that over and over again... Are all solo performers advocates?

RM: I think at least the way I think about my work, I may use my body and my voice, but what I try to do... I don’t... What I try to do always is take whatever thing in the world is pissing me off, or what I do want to say something about it — what I try to do is take that thing and use my body to make a comment about it, and in a way... I suppose with this piece, it was more personal because it was my epilepsy but... now I’m not sure... I’m not sure... I suppose what I’m unsure about what you said... I’m not an expressionist — and I’m not somebody who is interested in sharing one’s experience, so not sharing my experience. Because of who I am and what I have... how I can use those things to play with the cultural conscious, and throw them back... Maybe it’s advocacy still, but still different than saying “this is my experience”...

BL: I think, regardless, you’re going to be read like this anyway. No matter what, you are the person on display. Even if it’s not the way you frame the reading. And finally, How did that experience shape what happens next?

RM: The second piece, you know what’s really interesting. As well as this having marked a shift — coming out as a person with a disability — I made a decision last year when I got this funding to make this funding, to shift my practice. I’m originally from a dance background, and I haven’t been doing contemporary dance work — in the strict sense of the word — in a while, people who say my work was visual theatre, sometimes live art, but it was still anchored on processes I had been doing for a while. So I decided to throw my rule book out the window and start from scratch. The process of making was a process I had never done before. I was lost most of the time. There was no rule book. The work has some echoes of the first work. The cage is there, the sense of voyeurism is there... My initial idea was if I had had a seizure [in *Involuntary Dances*], I would have footage of that being what was in the box. But I didn’t, so I used other elements of it — so the voyeurism, the play with the audience and the idea of waiting. All the audience did for 24 hours was waiting — waiting for something that never happened. In terms of new processes and new products — it’s interesting in those ways — I’m really excited about it. I don’t think I was completely successful — I’m quite critical of *She’s Lost Control* and what I created, but in terms of my practice moving somewhere else, I’m very happy... it took me to a place I didn’t know I could go.

BL: About the 24 hours of waiting... how did that feel to you... was it a success? What was the feeling of not having a seizure.

RM: Awful. Awful. I felt like a failure, a huge failure. When you feel when you’re a performer, you want to put on the show. That’s what people have paid for. As a dancer, I would have practised, I would trained, I would put on the best show my body could do. And this time, my body didn’t do what I thought it was going to do, and I couldn’t practice it. It was really frustrating. And halfway through I got pissed, which I haven’t done for 20 years — because I don’t drink — so I lost, there is a period of a few hours that I don’t know how I felt. I remember coming out of it and thinking “oh I got pissed”. I got really angry as well...

BL: It was an affirmation of the loss of control.

RM: That was the irony of it. Maybe, and I kick myself a little bit. So many restrictions were put upon me — having to do with health and safety — so I couldn’t actually push myself further, because I could only drink x amount of glasses of wine, and I kick myself a little bit for that. In a way I should have done this, not as a paid gig, I should

have just done it in my house, thrown a party, and I still think I might do it one day, not advertise it, just as a party. The idea that I was going to be in control and make it happen, and for the first time in my life, to control the seizure, and then it backfired... it was really frustrating.

BL: In the narrative of Rita Marcalo's dance piece... Is it a sad story? Is it good that you didn't have a seizure?

RM: From outside or from me? From outside, there's two stories: there's the artist's perspective, who like my other head understands it as the work wasn't actually about that particular event happening or not. And that goes alongside the Rita that is really angry that it didn't happen, there is this Rita that knows that this was always possible. And then there's the other voices which I've seen written about which see it as a failure, or even worse than that... what's the word... hoax... It's not quite a hoax... Like she was always never going to have a seizure... They wrote "How do we even know this woman has epilepsy?" There are the voices that saw it as this failed because she didn't have a seizure or that it was a hoax.

BL: Critically people are interested in failure, but it's not satisfying as a performer...

RM: I have the two voices in my head — and they both have validity. One more thing, if you're looking at the relationship of this work with institutions... even though this relationship with Bradford Playhouse and it was the absolute perfect place for me to do it, and the Arts Council was really supportive, there were other institutions that I was linked to that have kind of not been so supportive. That has actually made me consider how I place myself and who I work with. There have been suggestions that my work, in the future, has to go through ethics committees. I just thought "No..." I found that really difficult but it's helped me shift to a different place.

Appendix B

Interview with Bobby Baker
London, 15 February 2010

Brian Lobel: I'd love to get your thoughts on this. I'm writing about the relationship between performance and advocacy and the difference between advocacy and spokesperson-ship. The first example that I'm looking at is the I'm Too Young for This advocacy campaign [I explain about the bracelet campaign mentioned previously]

Bobby Baker: That's so interesting because that's very much what I'm thinking about: What society can bear, what they can cope with and what you're supposed to be. And how you're supposed to react, which is ultimately to do with making other people feel better. I can't imagine anything worse than being the parent of a child who is going through that, but at the same time, the weight of social propriety stops anybody being who they are, whatever age, actually. Because I know what I'm supposed to be. It almost forces you to be the stereotype, doesn't it?

BL: The reason why I'm particularly interested in this issue, in relationship to your work is that so much of your work has to do with etiquette. I'm interested in what you see as the relationship between solo performance and that etiquette... I wonder how that etiquette affects the work you do around mental illness and the relationship with the Wellcome Trust.

BB: I had two experiences with the Wellcome Trust, the first one was totally to do with performance [*How to Live*], and not being overtly out. I'm astonished now — so many people didn't realise that I was mentally ill. Looking back at it, I was terribly ill at the time, but functioning well under the pressure. I now have a better understanding of what people were assuming about me. The misunderstanding there was. The wall I had built around myself in relation to the world that I operated in — and different levels, like my family — we're recovering, slowly, stage by stage. And the kind of complete ignorance or innocence of others. That was the first time that I had an interview that I talked publicly — it was extremely difficult with Lyn Gardner and she was embarrassed and I was embarrassed and we were really trying, but... And then I had these amazing set of relationships with professionals who didn't quite understand, but were very supportive of, me and really understanding what the show was about... So it was weird with me, in the middle, negotiating... And then doing this staggeringly public show, which was absurdly ambitious.

The extent of the ambition had to do with the head of fury I suppose at that stage — or a need to proselytise or need to make public what was happening... I realise now that the people I worked with really closely, they really didn't get it. They didn't understand what the show was about. I think if I realised how alone I was at the time — I couldn't go on. But you're on a mission that you somehow negotiate it. It did have a great affect on my life and my health — I was physically burnt out. I don't regret it. I think what I regret is going into the fellowship at the same time because of money worries. But the actually show, the performance, was very worthwhile.

The whole process was very risky for my health, but I was sort of on this mission. But at the same time, with this kind of determination and some kind of necessity to do it, this extraordinary energy... Funny enough that what happened was this kind of phenomenally cheering show — where, in many parts, I did protect those people who saw the show, from how ill I was. That was kind of the deal I cast... if they had really known what had happened to me. So there was this unconscious need for them to see how I learned to cope with those 11 skills, to get a sense of poignancy with the patient and the image of the pea, and actually probably not been able to — because of where I was personally — but also with an intuitive sense of wanting to protect people, to say that this pea was me. So I put myself in the role of the therapist

and that was directed by my desire to get at the expert but also to celebrate them — it's a very ambiguous position. But by doing that, taking that kind of power and knowledge, which I learned gradually... I'm fascinated by their skill and their way of thinking, and to kind of negotiate that relationship... it was a really crazy situation, and yet it worked. It sort of worked in a curious way in many phases. Because in the next four years, the show became a very small show that I did with Sian Stevens, and this ultimately became the show which I felt was the best resolution.

BL: When you talk about protecting the audience — do you mean a theoretical audience, a performative audience, the audience generally, or the audience as in “I know Dora's going to come to the performance...”

BB: It was for everybody. There were different versions for everyone single person I could imagine. I have always had the state of mind where I try to imagine the position of everyone in the audience — I think it's partly why I went mad — I think it's just my way of being... it's the theory of mind, that's the psychologist jargon. Putting yourself in other people's shoes... And I've always had a rather generous proportion of that. So if things become distressing I spend my whole time worrying about everyone else, forgetting who I am. So it's always been natural to me to think about what others are going to get out of what I'm doing. Sometimes it's gone a bit too far. But having an awareness of that, and a fine balance — I do wonder what people will think about what I'm doing — if it's irrelevant to them, but this other side which is the saving... ‘Well I don't really care because you're just going to bloody see it and I'm going to make it funny and engaging and entertaining... I don't have any answers to this’. It's kind of a cunning way of getting people involved. So when I did that show, I was, I think, quite knowingly putting a spin on things. I do think very strongly it's a sort of — it's partly based on experience, experience of performing, of winging it, hoping for the best, playing to the audience, and I think I was probably on the cautious side about how I made it about myself, but that was necessary for me at the time.

BL: Were there any moments in *How to Live* that were dangerous?

BB: I still think I'm dealing with the repercussions... Family involvement... I was concerned about the stories I said about them. I was very concerned about the stories about Andrew and my mum. I rather wove one in about Dora — about going shopping with her — because I don't want to make her feel left out. I'm still kind of ambivalent about that.

BL: And then, thinking about *Diary Drawings* in relationship to protection. To me, there seemed like something in the production which was all about protection. Dora consulted on what was included in the show, and Andrew took the photographs... much like the box with private comments available.

BB: An enormous amount of care went into that show, by Dora and I. Particularly Dora... I just find it hard to read hers without weeping. Protection. Protection. Protection... It was a frenzied concern for people — the list of helplines, the books that were chosen. And I think from the response which has been quite amazing, people felt quite cared for. We chose the most bearable stories. Andrew photographed all of them, which was about 190 of them... It was a pretty harrowing a process. We could curate them — it was so difficult to edit it. We used to say — ‘we have two images of you breaking in half — we can't have three...’ I remember having these weird conversations with my daughter. We were protective — terrifically caring — and this is not meant in a kind of self-congratulatory way, it was more about responsibility.

BL: Do you think the theme of protecting the audience has always been present in your work?

BB: I've always done that... When I started doing work — I've always had that concern. When I started doing that work in the 70s I was an angry young woman, a feminist, but I always wanted men to hear. What's the point of just swirling around? That was right there from the start — to varying degrees of success or failures...

BL: Does the imperative feel different?

BB: I want to be protected as an audience member.

BL: But I think I mean, when speaking about mental illness, in a context like the Wellcome Trust, did it feel like “now I have to protect this audience?”

BB: It was an extreme version because that version, it's a very extreme story... it's just very frank. I didn't know what it would be like on that level. It was like an unstoppable engine — because I just thought that these are pictures that need to be shown. There are a lot of pictures but they are always marginalised as pictures by sick people...

I remember the first meeting at the Wellcome Trust. We had met people individually, but this was the first time that we would all be together. It was me, Steph, and Dora. We were all a bit amazed by the Trust. But they didn't know what they were going to get — including Steph and Emma. Steph was saying ‘You know, this could tour immediately’ and I thought ‘Um, I'm just opening my life and I don't know whether I can cope with whatever...’ and Dora, one of her gifts, she said ‘I would imagine that for Bobby to do this will take a bit of time’. I can't remember exactly how she said it — it was sort of like ‘Hold on a minute, this is a very big deal’ and then of course everyone said ‘Oh yes, of course, of course’.

I feel something somewhat ‘sacrificial’ — that sounds a bit over the top. Sometimes I wish, sometimes I shouldn't be doing this. Is this a good idea? Is this wise?

[We break]

BL: Did the weight of social propriety, as you describe it, come out in the process of working on *Diary Drawings*.

BB: This was all going on [the difficult issues with final painting and completing her project] through this complicated process of negotiating what they all thought of me. They were all quite shocked by some of the drawings, but also quite excited by them. I also knew that I was ok, and I was dealing with my own horror of looking back at it and protecting myself. I was initially quite concerned for Dora. We were all quite shattered for a couple of weeks by that — going through the 700. There were all those real concerns about people who are close, who are loved, and whether Andrew and Charlie got into it... and I was recovering from chemotherapy, and I didn't have my hair back and so people were pretty horrified by that... and the medication that I was on made me put on all this all of this weight... but I knew I would be ok. I now realise that people were trying to compute who I was and so there was this sort of stubborn pride and also fury and distress about what I'd been through, and what we'd been through, and the injustice of it all... but the real problem was my bloody leg, my arthritis. I knew it was appalling...

There were just so many things going on. Physically it was terrible — people were trying to relate to all of that [the drawings], and I just wanted to scream, I was so tired, I could barely move. I was still a bit weak and though but also, it was so exciting doing the show, but standing was awful and walking... but I couldn't just stand and shout and say “get me a chair” because I was so worried what people would think. But that was what obsessed me the whole time... I wanted to get this bloody exhibition open so that I could get my knee fixed and disappear.

And as the pictures went up, people began to tell me their stories — and more and more... So Rosie [the public programs manager]... she's terrifically good, but she didn't realise, no one realised what was going on. I know that no one could have known how much physical pain I was in. Honestly it was just so crazy...

And we had a terrible problem communicating to the marketing. I know they were scared of me — because I had come up with the title *Bobby Baker, Diary Drawings: Mental illness and me*. Because I was trying to think... how to make it accessible and I was really pleased with the idea. We had this meeting with this woman Rachel and her assistant.... She just didn't realise how to cope with the pictures... and I later realised she was just embarrassed... She was put in a difficult situation of having to market this alongside *Madness and Modernity*, which had these extraordinary images...

All the way through, they were tiptoeing through the fact that I was mentally... they didn't know that I was well... They didn't know that I was well, they had seen these terrible pictures... they hadn't seen the final picture (because it hadn't appeared)... but we're scared of these pictures, but we have to sell it.

And all that I cared about was my knee — there they are all... they are all concerned for me... and not knowing what the problem was... and I'm trying to keep a stoical dignity and smile.... And then, as it went on... it went crazy with people telling me their stories about their aunt, their sister, their selves... Everywhere in that building was someone with a problem. Every person who got excited by something they had seen. So the pressure got worse and worse. Personally I was terrified how people would respond.

And the talks! I was so tired, that the only way that I could cope was to not stop talking... people were completely overwhelmed by me. And I am thinking... I have sat in crisis houses, and psychiatric hospitals and met these wonderful people and day centres and groups and listening to everyone's goddamn tale about their goddamn life about their father who abused them and you just think "shut up enough... let's have a laugh..." and then to come out about it in such a way and then to hear every goddamn story about their aunt and their mother and I couldn't give a shit, actually... "Look at the pictures, read the thing and give me a chair because I've got a bad leg."

BL: I'm curious if there was a tension between the mode of conversation — how it was going to be marketed, or if there was pressure...

BB: It was embarrassment... I couldn't understand ... What was going on in that whole weird phase... We couldn't get what was going on... We're pretty clued up about marketing... We couldn't get a handle on what was going on — and people were tiptoeing around... There were a lot of rows going on within there... When I did a debrief with Rosie afterwards, I told her that it would have been so much easier to come in and sit down and be told the truth because I could have sorted it... I would put your mind at rest.

This poor assistant had written this bit of marketing copy — and she only had bits and bobs of things. And it was just appalling as a starting point. She had used all the words you couldn't use. You know, if it's your story you can say Bonkers or I'm a Nutter. And it was an interesting education process for all of us, because I had to make it clear — if it's in inverted comma — then you can use that language. But I also know the political, psychiatric world. The language was the hardest thing I was ever involved in with that. All of us keeping an eye on those words — do you say Mental Health problem? Mental health difficulty? It's such a minefield, and I have strong feelings about it. And it's also marketing — and we're pretty canny about that. You want people to be able to read it, and they didn't get it because they were so embarrassed and worried — but also they wanted to sell it. There was an extraordinary bit at the end when the marketing woman had relaxed and she realised that she didn't get me at all — she saw the show and then it all relaxed.

They do this thing called Word Soup — when they have one of their images... they have hundreds of different words that they put into a soup — a digital program...

and so she started by then emailing me directly... That's when she got it — I put in hundreds more, really politically incorrect ones and also relevant diagnoses and she didn't get that my concern was genuinely about marketing, it wasn't about me...it was about selling the product, understanding the market, and that's market in the widest stance.

That was just so hard. I couldn't say just look... it's alright... you can say anything you like to me — but we really know this better than anyone, and we really want to sell the show. They couldn't get it. But we persevered and it worked out really well.

BL: Sounds a bit like the Arlene Croce situation, denying people with terminal illness the ability to be critiqued. You were thinking, as an artist, about your career, and people were still thinking about your mental illness first and foremost.

BB: And the banners... they had these banners that they put outside... They chose the running away from depression image — by then, we just kind of accepted the least work, but we all felt, doggedly, that the two mouth was going to be the most popular image. They changed the banner after a month — I don't know why — but the banner of the rest of the three months...

BL: Do you think it had to do with their personal discomfort around mental illness....

BB: Yeah.

BL: And probably appropriately. They shouldn't speak about it in the bold confident way that you could.

BB: It was a really painful educational experience. What's so great about them, even though there is a degree of embarrassment or political correctness, is that they are passionately committed — as part of their jobs and as individuals — to make this available to the public. So it was a really sensitive issue to them. Because people were really well-intentioned towards us it kind of resolved itself really well. It was fascinatingly frustrating. And the bit that bothered me the whole time, and I did rant a bit, was that what I was aware was that there is a skill in making the painting was likely to be much more accessible and praise-worthy than the skill in making performance... and it just bugs me, about society and the art world. The hierarchy of skill. Painting is very much at the top of... People are so stupid. So I was annoyed with myself for caring about that so much. I was annoyed but I was really annoyed that I knew that... but what happened that was completely wonderful was that it didn't matter at all... I was just glad that I learned how to paint because people actually got the story in a way that they wouldn't have gotten in any other art form. And I just felt so lucky that I had that opportunity and we had all that support from the organisation. It was worth that grief because it reached a very wide audience... if you had sat and watched a film. There was no other way... I did the diary quite genuinely at the time — so that clearly enables people to see a progression and me ultimately... in terms of style and subject and image... So that felt amazing. The whole thing felt amazing.

BL: And there is something about the situating of the Wellcome Trust, where it's located, how its free, etc...

BB: The thing about marketing that was so exciting — Tube adverts. Where would you ever get the chance to do tube adverts, really beautifully designed...

BL: And you don't have to do it yourself.

BB: They just do it. We kept going around saying 'pinch me'.

BL: A final question, and we discussed this before at Queen Mary, I was thinking about your talk in Newcastle and how they changed your bio. I am thinking about who has the language, how this interacts with the institution, etc. Would you tell me about how that resolved?

BB: It's a little moment of negotiating the relationship between the people who have the language... They were again embarrassed. When you meet people you understand that they mean well. I kind of worked out what had happened there. My friend is a Senior Lecturer there... We got there and I said to something to the woman in charge of the public lecture series... I laughed and I made a joke about it ... "You had to change that..." "Oh, sorry, sorry..." It was fine, and it turned out to be a very public lecture. I think I probably talked about it. It wasn't the bio it was the marketing pitch... I had been quite witty. It would have worked... * but I think what they said was that it was World Mental Health Day and they didn't want to offend anyone. and in fact, they wouldn't have done... but they didn't know what they were getting. and I was quite accepting. I was sort of annoyed and then I thought "hang on a minute — people still are very embarrassed about this — and it's a shocking subject and have a bit of humility, or patience..." Have a bit of patience about all of this. It was again like my irritation at the Wellcome. Being too impatient, wanting to say it all in one go. It's all about the caution and patience that the people who are marketing have to do. It worked. I feel so unbelievably fortunate that it all worked out.

BL: This humility is interesting. It's interesting to hear you speak, as an artist, there's some nice tension — productive difference. With marketing, you're like "We can't use this image because it's not going to get people" whereas in Newcastle — there is almost this moment of Greater Good. "I'm not going to bother with it because they don't want to offend people and that's ok because I actually care about speaking about this work in this context." At some points when creating artistic work about mental illness, there is a passion to create a work which de-stigmatises, and then an artistic impulse to speak correctly to an audience which has a lot to do with the tone.

BB: In Newcastle, I knew that problem was that the people in charge of the marketing were overprotecting the audience — being paternalistic, or maternalistic — underestimating the audience. And I knew as an artist that you didn't have to do that. I think it's that tension to think "I don't want to overestimate what the audience can take".

There was a curious experience with *How to Live*, where I had been very conscious with the words — and the Barbican was great to work with... I think I met a woman just randomly — a Samaritan, and I don't know if I met her, I know I didn't know her, I had met her after she had seen the show... So we were talking about the show... obviously she knew a lot about, she was interested. And she said that she had walked through the tunnel to the station... and it turned out she was walking with someone to the show... It turned out that they were both going to see the show. So why are you coming to see the show... She said I'm coming to see the show because I'm a Samaritan but I had asked my other friends if they would come to see the show and they said, they looked at the publicity material and they said "No, I'm not going to see a show about nutters." And I was amazed — because if you look at the marketing for *How to Live* it so doesn't look like it's about that. But this was a woman being very frank.

So I was really conscious of the marketing — I'm not trying to embarrass you, or to upset you, I just want you to see the show. But I'm also really worried about people then turning you into this hero, or heroine, this noble, brave survivor. It bugs me. It just so bugs me. Because I know people who are nobler and braver... But this is about, Dora and I talked about this endlessly... I mean we want to make a buck [laughter] and all that... But it's more about, trying to let people in. My view of making work, then people go away and they think about, not about you, but about their own lives... or

themselves and the shows I know that I was very excited... *Box Story* or *Drawing on a Mother's Experience*. You know, people related to those. They are not actually thinking about you so much as they are about themselves... With *Diary Drawing* it was 'I want you to think about your experience or your friends', or 1 in 4, 1 in 4, or just think about your own bigotry... but then when it becomes about idolisation it becomes really uncomfortable.

BL: And this leads to my last point that I wanted to talk about. Is any kind of solo performance — any time when someone puts themselves in front of an audience... is that the inevitable, that someone gets put up as an advocate, as a spokesperson?

BB: I found myself really caught up in being a spokesperson, service user rep, I got so politicised. And I was a fountain of facts... all I could do was quote statistics... and rattled off figures about the Holocaust... the number of people, psychiatric patients who had been killed... It was exhausting and overwhelming and I was really learning a lot. I finally got "Hey, I'm an artist. I'm an artist, actually." There are people who do that really well. There are people who do training... I'm this, and if things work, I'm funny. That's all I can do. That's my contribution. So that was helpful. And also the feeling "this is not all my life — I'm going to create work on other things" and just, I haven't really, I haven't figured this one out. I'm quite worried about it.

BL: And that was what that was — *Diary Drawings* was a piece of advocacy.

BB: Totally, that what our aim was.

BL: The tension arises when Bobby Baker does something outside of the box that we're comfortable with. In a way, *How to Live* is interesting in this regard — you playing the explicit role of the spokesperson. You were playing the authority.

BB: I think I had to do that because I felt so pea like.

BL: The authority is really stripped away in *Diary Drawings*

BB: One example of it — it had to be a group mission. I had to feel like I was part of this incredible team. We were because we all got tied up. There was this ridiculous thing. there was this ridiculous one weekend before the deadline, and I was just being dogged — and one of my oldest school friend's son had a breakdown and I had to be with the family... I had done a lot of the research, but also a lot of procrastination... I had done the first section, and everybody liked that, and all I had to do was the other 16. I started working at 5pm and it was due the next morning... I just sat on my sofa, and... It was just awful... It was like writing an unedited book. It was 80-150 words to the section heading. They kind of know... The captions were 50-80 words maximum. That's really disciplined. By the end, the captions, I think it was 3 in the morning... No matter how much I wrote and wrote I couldn't do it. And I thought "Emma" I'll look at the team...I couldn't have done it on my own. I didn't have the objectivity to do it on my own, without my team.

[We stop there to have supper]

Appendix C

Contextualising Statements by Dr. Sue Gessler — *Tommyknockers* Action Statements accompany documentation online at <http://www.youtube.com/watch?v=llji3PIAEYc>.

‘Surgery’, ‘Recovery’, ‘Procedure’, ‘Negative’... What’s going on with the language is that you’ve got words which are normally so neutral and they suddenly become charged. Some words have an ordinary lay meaning but have an exact meaning for medics which may be quite different. A classic one is ‘Progress’. The word ‘Progress’ is normally quite good in the outside world. When a doctor says that your disease is progressing, you think “Oh Great!” whereas Progressive Disease means that the disease has progressed during treatment — that it has continued growing while we’ve been giving chemotherapy. Same with positive and negative. Usually positive is a positive thing, and negative a negative thing, but not so in the case of diagnosis. An ordinary word is taken and given an exact meaning in their world, and it is pulled around willy-nilly for you, the patient.

Do you need to give up your internal mental and linguistic structure in order to be able to relate to what the doctor is saying? Do you need to hand over the whole of your mind? Do you have to be a cancer expert? What happens to your personal understanding of language when you learn to speak Cancer?

With trauma, words stop having their symbolic meaning. The word trauma comes from a piercing through armour — it means that something gets straight to your core. One of the things that’s really odd about cancer is that seemingly-symbolic words become literal things. For most people, cancer comes up symptom-free. You go in with something worrying and then this doctor says these words to you and those words are radiotherapy, surgery, chemotherapy. Suddenly there are these words — for which you previously have no referent — which become things inside you doing terrible things...

Here, Laura is taking back words. She is saying they are just words, and though they have been very painful, they can go back into thin air. She is allowing herself, simultaneously, to get a sense of self back by reclaiming the boundaries around herself and rebuilding her armour and defences. Everyone wants to go back to how they were before, and that’s the disaster. It’s never going to go back. Most of our generation don’t believe that anything bad will happen to them, ever. With cancer, fantasies about omnipotence and fantasies about immortality are thrown. Once you know there can be situations where one is forced to leave their comfortable life, you can’t un-know that.

Appendix D

Contextualising Statements by Dr. Sue Gessler — *Guerilla Pub Quiz Action*
Statements accompany documentation online at <http://vimeo.com/10527523>.

Chemo brain is really really interesting because there's been a long history of patients complaining about it and people rather ignoring it because it's not "sinister". Everything to do with cancer is ignored if it's not about the illness itself. These things were seen as small problems on the way.

After chemotherapy, there is definitely a loss in concentration. Whether this actually reflects a change in capacity, I would need to check. I think the problem is that even after you're diagnosed, you're in this trauma state — you're dominated by other thoughts... your processing capacity of just taking in new information, working memory, all of those things, is reduced because so much of your computing capacity is taken up just processing what's around you "will I die?" "what will i do?" all of that. there is an argument that one of the problems is the processing capacity.

I do have patients who say they find it very hard to get back into reading books, concentrating — but they have been through a trauma. I don't know if it's drugs? Or trauma? Or both? With cancer, your timetables change, your food regime changes, your sleep has changed... It could be a bit of everything coming together.

There's something about looking at breasts. You learn to look and not to look and you learn that there are ways of looking at somebody's body that are not unacceptable. There are ways that you manage to look at something while not looking at it. But there's the secondary issue, which is desiring to know what the breast reconstruction looks like. Breast cancer makes people into an audience of small children who want to stare. Here, Laura is giving them permission to stare.

In ordinary walking — walking down the street — you glance at someone, and then you look away. If anyone's got something that's got something unusual, suddenly your eyes go back to it. If you're that person, you see heads turning all the time which is actually, largely speaking, unconscious. This inability to legislate people's reactions is an essential problem someone with stigma deals with.

The breast thing is very important and separates breast cancer patients from women with other cancers. We're talking about things which make women women. For many breast cancer patients — you have this sense of a part of you, which clearly identify you as a woman. Compared with gynaecological cancer patients who are dealing with their vagina, their cervix, their womb, things which are intrinsically 'woman' but are hidden, they often feel something very important has been taken away and nobody can see it. This breast thing is so upfront, and there is this sense that people can look, but what about these other women?

Appendix E

Contextualising Statement by Head Nurse Anne Lanceley — *Guerilla Pub Quiz*
Also available with the online documentation cited above.

I've been caring for people with cancer for 30 years and only recently heard the term Chemo Brain. I think it's generated by people with cancer talking to each other. It's a cancer-sufferers or -survivors terminology which is not a medical language. It seems empowering that it comes from the grassroots and not that it originates from a doctor.

Once patients have the term, the label Chemo Brain, it makes sense of a lot of their experience. Just as the cancer diagnosis, in a way, makes sense of a lot of the symptoms which have lead up to diagnosis. For many, diagnosis is a relief. Similarly, by saying "Oh it's Chemo Brain" — behaviours are allowed whose causes were previously unknown. With cancer, you can't trust your body, you can't trust your memory. In a way, Chemo Brain is like a medical term for disillusion — a term for the overall loss associated with cancer.

Having chemotherapy causes a trauma because of the process your body experiences in which something very poisonous is being put into your bloodstream. The very action runs counter to one's previous experience, in that taking things into our body, such as food, is usually a pleasurable action. Psychodynamically, to put poison into our body is very horrible and ugly. It affects bodies and psyches in ways that are quite beyond many people's capacities.

When people get ill, they regress and the body's primitive functions are reawakened. If someone is physically ill, their body is touched, turned over and handled in a way that they have not experienced since when they were a baby and all of that is very traumatising. As a nurse, if I can hold their head than I feel pleased that I can do that for people. But it's not an easy thing for many people to accept. It's a hard thing for people to feel so vulnerable.

Most of what people with cancer experience they experience on their own. They wake up and they are sick and they go to the toilet on their own. A lot of what the person has to experience is unsharable. Others can never know what your pain is like. It's not my stomach ache, it's your stomach ache. Chemo Brain too, is unsharable. It's tantalising to want to know what someone's experience is, but it's impossible. You try to understand what someone's abdominal pain is, for instance, but you just don't know.

Bibliography

Adorno, Theodor, 'Commitment' in *Aesthetics and Politics* (London: Verso, 1977), pp. 177-195

Allen, Clare, 'Bobby Baker: Pull Yourself Together' in Adrian Heathfield, ed., *Small Acts: Performance, the Millennium and the Marking of Time* (London: Black Dog Publishing, 2003), pp. 127-135

Anderson, Benedict, *Imagined Communities: Reflections on the Origin and Spread of Nationalism* (London and New York, Verso, 1991), p. 1-8

Armstrong, Lance, *It's Not About the Bike* (London: Yellow Jersey Press, 2001)

Auslander, Philip, *Liveness: Performance in a Mediatized Culture* (London and New York: Routledge, 1999), pp. 1-10, 43-63

Baker, Bobby, *Diary Drawings: Mental Illness and Me* (London: Profile Books, 2010), pp. 1-16, 207-215

Barnes, Colin and Mercer, Geof, eds., *Exploring the Divide: Illness and Disability* (Leeds: The Disability Press, 1996), pp. 2-17

Barrett, Michèle and Baker, Bobby, *Bobby Baker: Redeeming Features of Daily Life* (London and New York: Routledge, 2007), pp. 3-22, 95-109, 135-144, 246, 251-267

Barthes, Roland, *Camera Lucida* (New York: Hill and Wang, 1980), pp. 85-100

Barthes, Roland 'Death of the Author' in *Image-Music-Text* (New York: Hill and Wang, 1982), pp. 142-148

Berwald, Olaf, *An Introduction to the Works of Peter Weiss* (Rochester: Camden House, 2003), pp. 22-32

Blanchot, Maurice, *Friendship* (Stanford: Stanford University Press, 1997)

Bonney, Jo, *Extreme Exposure: An Anthology of Solo Performance Texts from the Twentieth Century* (New York: TCG Press), pp. 187-196

Brian's Song, dir. by Buzz Kulik. (Screen Gems Television, 1971)

Brodzinski, Emma, *Theatre in Health and Care* (Basingstoke: Palgrave Macmillan, 2010)

Broyard, Anatole, *Intoxicated By My Illness* (New York: Fawcett Columbine, 1992)

Butler, Judith, *Gender Trouble: Feminism and the Subversion of Identity* (London and New York: Routledge), p. 177-179.

The Bucket List, dir. by Rob Reiner (Warner Bros., 2007)

- Caruth, Cathy, *Unclaimed Experience* (Baltimore: Johns Hopkins University Press, 1996), p. 1-9
- Crimp, Douglas, 'AIDS: Cultural Analysis/Cultural Activism', *AIDS: Cultural Analysis/Cultural Activism* (Cambridge, Massachusetts: MIT Press, 1987), pp. 3-16
- Currie, Mark, *About Time: Narrative, Fiction and the Philosophy of Time* (Edinburgh: Edinburgh University Press, 2007), pp. 1-28
- Davis, Lennard J., *Bending over Backwards: Disability, Dismodernism & Other Difficult Positions* (New York and London: NYU Press), pp. 1-32
- Derrida, Jacques, *Archive Fever: A Freudian Impression*, trans. Eric Prenowitz (Chicago and London: University of Chicago Press, 1996)
- Dolan, Jill, *Utopia in Performance: Finding Hope at the Theatre* (Ann Arbor: University of Michigan Press, 2005), pp. 1-34, 35-62
- Ehrenreich, Barbara, *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America* (New York: Metropolitan Books, 2009), pp. 1-44
- Elber, Lynn, *Lakewood Ledger*, 26 March 1996, A5
- Flanagan, Bob, *Fuck Journal* (New York: Hanuman Press, 1987)
- Flanagan, Bob, *The Pain Journal* (Los Angeles: Semiotext(e)/Smart Art Press, 2000)
- Flanagan, Bob, *Supermasochist* (San Francisco: Re/Search Publications, 1993), pp. 6-29
- Frank, Arthur W., *The Wounded Storyteller: Body, Illness and Ethics* (Chicago: The University of Chicago Press, 1996)
- Garland-Thomson, Rosemarie, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), pp. ix-xx, 5-18
- Garland-Thomson, Rosemarie, 'Narratives of Deviance and Delight: Staring at Julia Pastrana, the 'Extraordinary Lady'', *Beyond the Binary: Reconstructing Cultural Identity in a Multicultural Context*, ed. Timothy B. Powell (London: Rutgers University Press, 1999), pp. 81-104
- Garland-Thomson, Rosemarie, *Staring: How We Look* (Oxford: Oxford University Press, 2006), p. 3-48
- Goffman, Erving, *The Presentation of Self in Everyday Life* (London: Penguin, 1959), pp. 12-27

- Grealy, Lucy, *As Seen on TV* (New York and London: Bloomsbury, 2000), pp. 5-20, 29-46
- Grealy, Lucy, *Autobiography of a Face* (New York: Perennial, 2003), pp. 227-236
- Grehan, Helena, *Performance, Ethics and Spectatorship in a Global Age* (Basingstoke: Palgrave Macmillan, 2009), pp. 1-35
- Gultenane, Christian, *OK! Magazine*, 10 March 2009
- Hart, Lynda, *Between the Body and the Flesh: Performing Sadomasochism* (New York: Columbia University Press, 1998), pp. 125-166
- Heathfield, Adrian and Tehching Hsieh, *Out of Now: The Lifeworks of Tehching Hsieh* (London: Live Art Development Agency, 2008), pp. 37-45
- Heddon, Deirdre, *Autobiography and Performance* (Basingstoke: Palgrave Macmillan, 2008), pp. 20-52
- How to Live*, Bobby Baker (Daily Life Limited, 2007)
- The Investigation*, by Peter Weiss, New Vic Theatre, London, dir. Dorcy Rugamba (2007)
- Iser, Wolfgang, *The Implied Reader: Patterns of Communication in Prose Fiction from Bunyan to Beckett* (Baltimore and London: The Johns Hopkins University Press, 1974), xi-xiv
- Jaworski, Adam, *The Power of Silence: Social and Pragmatic Perspectives* (New York: Sage Publications, 1992), pp. 140-165
- Jones, Amelia, *Body Art: Performing the Subject* (Minneapolis and London: University of Minnesota Press, 1998), pp. 226-238
- Joseph, Miranda, *Against the Romance of Community* (Minneapolis: University of Minnesota Press, 2002), pp. 1-29
- Kosofsky Sedgwick, Eve, *Tendencies* (Durham: Duke University Press, 1993), pp. 1-22
- Kron, Lisa, *Well* (New York City: Theatre Communications Group, 2006)
- Kuppers, Petra, *Community Performance: An Introduction* (London and New York: Routledge, 2007), pp. 1-14, 58-108
- Kuppers, Petra, *Disability and Contemporary Performance: Bodies on Edge* (New York and London: Routledge, 2003), pp. 1-48, 80-86, 122-134
- Kuppers, Petra, “‘your darkness also/rich and beyond fear’: Community Performance, Somatic Poetics and the Vessels of Self and Other”, *M/C Journal*, 12, 5, 2009

- Kuppers, Petra, *The Scar of Visibility: Medical Performances and Contemporary Art* (Minneapolis and London: University of Minnesota Press, 2007), pp. 1-24, 72-94
- Levinas, Emmanuel, 'Useless Suffering,' trans. Richard A. Cohen, *The Provocation of Levinas: Rethinking the Other*, ed. Robert Bernasconi and David Wood (London: Routledge, 1988), pp. 156-167
- Lobel, Brian, 'BALL', *Text & Performance Quarterly*, 28, 1/2, 2008, pp. 160-177
- Lobel, Brian, *BALL & Other Funny Stories About Cancer* (London: Oberon, 2012)
- Lorde, Audre, *The Audre Lorde Compendium: Essays, Speeches and Journals*, (Pandora: London, 1996), pp. 3-62, 269-335
- Lushetich, Natasha, 'On the Performativity of Absence: Death as community', *Performance Research*, 15, 1, 2010, pp. 81-89
- Lyotard, Jean-François, *The Differend: Phrases in Dispute*, trans. Georges Van Den Abbeele (Minneapolis: University of Minnesota, 1988), pp. 3-31
- Mason, Margaret, *No One Cares What You Had for Lunch: 100 Ideas for Your Blog* (Berkeley: Peachpit Press, 2007)
- Miller, D. A., 'Sontag's Urbanity', *October*, 49, 1989, pp. 91-101
- Miller, Susan, 'My Left Breast' in *O Solo Homo*, ed. Holly Hughes and David Román (New York: Grove Press, 1998), pp. 95-120
- Morley, David, and Chen, Kuan-Hsing, eds., *Stuart Hall: Critical Dialogues in Cultural Studies* (New York: Routledge, 1996), pp. 442-451
- Mulvey, Laura, 'Visual Pleasure and Narrative Cinema', *Screen*, 16, 3, 1975, pp. 6-18
- Mukherjee, Siddhartha *The Emperor of All Maladies: A Biography of Cancer* (London: Fourth Estate, 2011)
- Park-Fuller, Linda, 'How to Tell a True Cancer Story', *Text and Performance Quarterly*, 28, 1/2, 2008, pp. 178-182
- Patraka, Vivian, *Spectacular Suffering: Theatre, Fascism and the Holocaust* (Bloomington: Indiana University Press, 1999), pp. 86-108
- Phelan, Peggy, *Unmarked: The Politics of Performance* (London and New York: Routledge, 1993), pp. 146-166
- Phelan, Peggy, *Mourning Sex: Performing Public Memories* (London and New York: Routledge, 1997), pp.1-22

- Propp, Vladimir, *Morphology of the Folktale*, trans. Laurence Scott. 1968 (Austin: University of Texas Press, 1968), pp. 7-17
- Quick, Andrew, *The Wooster Group Workbook* (New York and London: Routledge, 2007), pp. 8-15
- Reason, Matthew, *Documentation, Disappearance and the Representation of Live Performance* (Basingstoke: Palgrave Macmillan, 2009), pp. 1-54
- Ribalta, Jorge ed., *Jo Spence: Beyond the Perfect Picture* (Barcelona: Museu d'Art Contemporani de Barcelona, 2005), pp. 18-30, 262-333.
- Rieff, David, *Swimming in a Sea of Death: A Son's Memoir* (London: Simon & Schuster, 2008), pp. 1-21, 139-157
- Rosenblum, Barbara, 'I have begun the process of dying', in Jo Spence and Patricia Holland ed., *Family Snaps: The Meaning of Domestic Photography* (London: Virago, 1991), pp. 239-244
- Rosenthal, Kairol, *Everything Changes* (Hoboken: John Wiley & Sons, 2009)
- Sacco, Joe, *Palestine* (Seattle: Fantographics Books, 2002), pp. 220-249
- Sacco, Joe, *Safe Area Gorazde: The War in Eastern Bosnia, 1992-1995* (Seattle: Fantographics Books, 2000)
- Sandahl, Carrie and Auslander, Philip, eds., *Bodies in Commotion: Disability and Performance* (Ann Arbor: The University of Michigan Press, 2005), pp. 1-12, 56-68, 129-146, 219-229
- Scarry, Elaine, *The Body in Pain* (Oxford: Oxford University Press, 1985), p. 3-23
- Schneider, *Performance Remains: Art and War in Times of Theatrical Reenactment* (New York and London: Routledge, 2011), pp. 1-60
- Seuss, D, *I Had Trouble in Getting to Solla Sollew* (New York: Random House, 1965)
- Shildrick, Margrit, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (Basingstoke: Palgrave Macmillan, 2009)
- Sick: The Life & Death of Bob Flanagan, Supermasochist*, dir. by Kirby Dick (Lionsgate, 1997)
- Sim, Stuart, *Manifesto for Silence: Confronting the Politics and Culture of Noise* (Edinburgh: Edinburgh University Press, 2007), pp. 155-171
- Snow, C. P., *The Two Cultures* (London: Cambridge University Press, 2001), pp. 1-21
- Sofaer, Joshua, *The Many Headed Monster* (London: Live Art Development

Agency, 2009)

Sontag, Susan, *Against Interpretation and Other Essays* (New York: Farrar, Straus & Giroux, 1966), pp. 132-163

Sontag, Susan, *Illness as Metaphor and AIDS and Its Metaphors* (New York: Anchor Books, 1990)

Sontag, Susan, *On Photography* (New York: Farrar, Straus and Giroux, 1977), p. 5-25

Sontag, Susan, *Regarding the Pain of Others* (New York: Farrar, Straus and Giroux, 2003), pp. 6-42

Sontag, Susan and Rieff, David, ed., *Reborn: Journals and Notebooks 1947-1963* (London: Picador, 2009)

Spence, Jo, *Cultural Sniping: The Art of Transgression* (London: Routledge, 1995), pp. 19-27, 112-128, 212-226

Spence, Jo, *Putting Myself in the Picture: A Political Personal and Photographic Autobiography* (London: Camden Press, 1986), pp. 82-97, 150-171

Sprinkle, Annie and Stephens, Beth, *Exposed: Experiments in Love, Sex, Death and Art*, (2006)

Stacey, Jackie, *Teratologies: A Cultural Study of Cancer* (London and New York: Routledge, 1997), pp. 1-29, 65-96, 201-245

Terms of Endearment, dir. by James L. Brooks (Paramount Pictures, 1983)

Thompson, James, *Performance Affects: Applied Theatre and the End of Effect* (Basingstoke: Palgrave Macmillan, 2009), pp. 1-77, 115-135

Thompson, Nato, *The Interventionists: A Users' Manual for the Creative Disruption of Everyday Life* (North Adams: MASS MoCA Publications, 2004), pp. 13-22

Walsh, Fintan, 'Between Deaths: Screening Jade Goody', *Contemporary Theatre Review*, 19, 3, 2009, pp. 382-385

Woolf, Virginia, *On Being Ill* (New York: Hogarth Press, 1930), pp. 3-28

Webography

'About Mediaplanet International', *Mediaplanet International*, <<http://www.mediaplanet.com/about#top>> [accessed 23 January 2012]

'About Seeds of Peace', *Seeds of Peace*, <<http://seedsofpeace.org/about>> [accessed 22 January 2012]

'About Us, Wellcome Collection', *Wellcome Collection*, <<http://www.wellcomecollection.org/aboutus/index.htm>> [accessed 1 October 2009]

ACT UP Homepage', *ACT UP/NY*, <<http://www.actupny.org/>> [accessed 30 January 2012]

'Annie Sprinkle's Bosom Ballet', *Annie Sprinkle*, <<http://anniesprinkle.org/projects/archived-projects/annie-sprinkles-bosom-ballet/>> [accessed 22 January 2012]

'Autism Awareness Home', *Autism Awareness UK*, <<http://www.autismawarenessuk.com/>> [accessed 22 January 2012]

Barrow, Karen and Jackson, Tom, 'Picture Your Life After Cancer', *New York Times Online*, 8 April 2010, <<http://www.nytimes.com/interactive/2010/04/08/health/cancer-survivor-photos.html?ref=health>> [accessed 3 March 2011]

Bilton, Nick, 'The Price of Facebook Privacy? Start Clicking', *The New York Times*, 12 May 2010, <<http://www.nytimes.com/2010/05/13/technology/personaltech/13basics.html>> [accessed 26 December 2011].

'Bobby Baker: Artist', *Newcastle University*, <<http://www.ncl.ac.uk/events/public-lectures/item.php?bobby-baker-artist>> [accessed 5 May 2010]

'Bobby Baker in Conversation', *Wellcome Collection*, <<http://www.wellcomecollection.org/exhibitionsandevents/pastexhibitionsandevents/wtx053589.htm>> [accessed 1 October 2009]

Brown, Jonathan, 'Artist to have epileptic fit live on stage,' *The Independent*, 20 November 2009, <<http://www.independent.co.uk/arts-entertainment/art/news/artist-to-have-an-epileptic-fit-live-on-stage-1824122.html>> [accessed 5 May 2010]

'Camps', *Cystic-L*, <http://cystic-l.org/handbook/html/cf_camps.htm> [accessed 16 May 2010]

'CarePages Homepage', *CarePages*, <<http://www.carepages.com>> [accessed 25 December 2011]

'Celebrity Wishes', *Make-a-Wish Canada*, <http://www.makeawish.ca/wish_stories/celebrity_wishes> [accessed 5 February 2012]

'Connotations, Hayley Newman', *Hayley Newman*, <<http://www.hayleynewman.com/artworks/show/15>> [accessed 24 April 2011]

'Coppafeel Homepage', *Coppafeel*, <www.coppafeel.org> [accessed 16 November 2010]

'Domestic Violence Wristbands', *Shanrene Jewelry & Gift Store*, <<http://www.shanrene.com/page/001/PROD/domestic-violence-wristband>> [accessed 22 January 2012]

'EARN: Epilepsy Action Research Network', *Epilepsy Action Network*, <<http://www.epilepsy.org.uk/research/earn.html>> [accessed 5 May 2010]

Ebert, Roger, 'Review of *The Bucket List*', *Chicago Sun-Times*, 10 January 2008, <<http://rogerebert.suntimes.com/apps/pbcs.dll/article?AID=/20080110/REVIEWS/801100301>> [accessed 26 December 2011]

Ennis, Jane, 'I created the monster that became Jade Goody Inc...', *Mail Online*, 7 February 2009, <<http://www.dailymail.co.uk/tvshowbiz/article-1138397/I-created-monster-Jade-Goody-Inc--Now-I-feel-guilty-fights-life.html>> [accessed 3 November 2009]

'Facebook Homepage', *Facebook*, <<http://www.facebook.com>> [accessed 25 December 2011]

Fernandez, Sally M., 'Pretty in Pink', originally printed in *MAMM Magazine*, June/July 1998, and available at *Think Before You Pink*, <http://thinkbeforeyoupink.org/?page_id=26> [accessed 29 January 2012].

Frazier, Mya, 'Costly Red Campaign Reaps Meager \$18 Million', *Advertising Age*, 5 March 2007, <http://adage.com/article?article_id=115287> [accessed 17 May 2010]

'Frequently Asked Questions', *Bradford Playhouse Homepage*, <<http://www.bradfordplayhouse.co.uk/rita/faq.html>> [accessed 5 May 2010]

Galvin, Cathy, 'Annie Leibovitz: Nothing Left to Hide', *The Times*, 5 October 2008, <<http://www.gg-art.com/news/read.php?newsid=22928>> [accessed 24 December 2011]

Gardner, Lyn, 'One moment, please...', *The Guardian*, 25 February 2011, <<http://www.guardian.co.uk/stage/theatreblog/2011/feb/25/brian-lobel-sell-minute-of-life>> [accessed 4 July 2012]

Grealy, Suellen, 'Hijacked by grief', *The Guardian*, 7 August 2004, <<http://www.guardian.co.uk/books/2004/aug/07/biography.features>> [accessed 2 February 2012]

Green, Jesse, 'The Year of the Ribbon', *The New York Times*, 3 May 1992, <<http://www.nytimes.com/1992/05/03/style/the-year-of-the-ribbon.html?pagewanted=all&src=pm>> [accessed 25 January 2012].

Hallenga, Kris, *Kancer & Kris: kristin's guide to gardening — nippin kancer in the bud*, 19 February 2009, <<http://kriskancer.squarespace.com/>> [accessed 11 November 2010]

'Illness', *Oxford English Dictionary*, <<http://www.oed.com/view/Engr/91493?redirectedFrom=illness#eid>> [accessed 2 February 2012]

Jeeves, Paul, 'Epilepsy: Rita Marcalo Receives Grant to Induce Fit on Stage', *The Express*, 20 November 2009, <<http://www.express.co.uk/posts/view/141313>> [accessed 10 January 2010]

Kilburn, Rosie, *The Knock-On Effect*, <<http://theknockoneffect.wordpress.com/what-im-doing-here/>> [accessed 10 November 2010]

Lobel, Brian, Jansen, Chipp and Okubo, Nako, *Fun with Cancer Patients Website*, <<http://www.blobelwarming.com/fwcp>> [accessed 24 December 2011].

Lopez Torregrosa, Luiseta, 'A Skirmish Over Women's Health Gets Political', *The New York Times*, 7 February 2012, <<http://www.nytimes.com/2012/02/08/us/08iht-letter08.html>> [accessed 8 February 2012].

'Lotsa Helping Hands Homepage', *Lotsa Helping Hands*, <<http://www.lotsahelpinghands.com.>> [accessed on 5 November 2009]

Mukherjee, Siddhartha, 'Should we stop trying to cure cancer?', *The Guardian Weekend*, 15 January 2011, <<http://www.guardian.co.uk/world/2011/jan/15/cancer-the-new-normal>> [accessed 24 December 2011]

Nicholls, Paul, *Music is Disease*, <<http://www.musicisdisease.blogspot.com>> [accessed 11 November 2010]

O'Rourke, Tanya, 'Controversial epileptic 'fit' performance ends in failure', *Bradford Telegraph and Argus*, 12 December 2009, <http://www.thetelegraphandargus.co.uk/news/local/localbrad/4790933.Dancer_Rita_takes_a_step_into_the_unknown/> [accessed 18 January 2010]

'Our Mission', *Make-a-Wish Canada*, <http://www.makeawish.ca/about_us/our_mission> [accessed 30 April 2010]

Parker-Pop, Tara, 'Picture Your Life After Cancer', *The New York Times Online*, <<http://well.blogs.nytimes.com/2010/04/08/picture-your-life-after-cancer/>> [accessed 3 March 2011]

Pela, Robert, 'Prize Fighter', *Generation Health*, <<http://generationhealthaz.com/cover-story/35-covers/123-tania-katan-prize-fighter.html>> [accessed 5 May 2010]

Performing Medicine, <www.performingmedicine.com> [accessed 16 November 2010]

'Real Time Cancer Homepage', *Young Adult Cancer Canada*, <<http://www.youngadultcancer.ca>> [accessed 25 December 2011]

'The (RED) Idea', *Join (RED)*, <<http://www.joinred.com/aboutred>> [accessed 17 May 2010]

Richards, Jane, 'Centrefold/Spence of self: Jo Spence used photography to battle illness', *The Independent*, 7 September 1994, <<http://www.independent.co.uk/life-style/centrefold--spence-of-self-jo-spence-used-photography-to-battle-illness-1447158.html>> [accessed 25 December 2011]

Rosenberg, Howard, 'HBO's 'Wit': A Touching, Unsentimental Look at Dying', *LA Times*, 23 March 2001, <<http://articles.latimes.com/2001/mar/23/entertainment/ca-41467>> [accessed 25 December 2011]

Rosenthal, Kairol, *Everything Changes Blog*, <<http://everythingchangesbook.com/>> [accessed 30 March 2011]

'Silicone Wristbands,' *LIV Village*, <<http://www.liv-village.com/blog/tag/silicone-wristbands/>> [accessed 22 January 2012]

'Statement on *Involuntary Dances*', *Epilepsy Action Network*, November 2009, <<http://www.epilepsy.org.uk/about/positionstatements/ritamarcalo>> [accessed 5 April 2010]

Stewart, Catriona, 'Remember me and have a good time', *Evening Times*, 1 September 2010, <<http://www.eveningtimes.co.uk/news/editor-s-picks/remember-me-and-have-a-good-time-1.1052151>> [accessed 26 December 2011]

'Stupid Cancer Bracelets', *Stupid Cancer Bracelets*, <<http://stupidcancerbracelets.blogspot.com/>> [accessed 22 January 2012]

Sturcke, James, 'Cancer tests go up after Goody diagnosis', *The Guardian*, 17 February 2009, <<http://www.guardian.co.uk/media/2009/feb/17/cancer-tests-jade-goody>> [accessed 26 December 2011]

'Sue Gessler Biog', *UCLH*, <http://www.uclhwomenscancer.com/biogs/sue-gessler.asp?keepThis=true&TB_iframe=true&height=567&width=740> [accessed 1 November 2011]

'Super Night Shot', *Gob Squad*, <http://www.gobsquad.com/currentsubpage.php?id_project=4> [accessed 3 January 2011]

Sutherland, Allan, 'Epilepsy as live art isn't controversial', *Guardian Theatre Blog*, 20 November 2009, <<http://www.guardian.co.uk/stage/theatreblog/2009/nov/20/epilepsy-live-art-rita-marcalo>> [accessed 1 December 2011]

Thomas-Bailey, Carlene, 'Young patients turn to blogs to make cancer public', *The Guardian*, 5 July 2010, <<http://www.guardian.co.uk/lifeandstyle/2010/jul/05/young-patients-blogs-cancer>> [accessed 10 November 2010]

'Time to Change Campaign Homepage', *Mind*, <<http://www.mind.org.uk/timetochange>> [accessed 4 November 2009]

Vallely, Paul, 'The Big Question: Does the Red Campaign Help Big Western Brands More Than Africa', *The Independent*, 9 March 2007, <<http://www.independent.co.uk/news/world/politics/the-big-question-does-the-red-campaign-help-big-western-brands-more-than-africa-439425.html>> [accessed 17 May 2010]

Verrent, Jo, 'Review: Jo Verrent sees Rita Marcalo's *Involuntary Dances*', *Disability Arts Online*, 12 December 2009, <http://www.disabilityartsonline.org/?location_id=1110> [Accessed 18 January 2010]

'The Voice that Launched the Jimmy Fund', *Jimmy Fund*, <<http://www.jimmyfund.org/abo/broad/media/broadcast.mp3>> [accessed 2 February 2012]

'Wellcome Trust Arts Award', *Wellcome Trust*, <<http://www.wellcome.ac.uk/Funding/Public-engagement/Funding-schemes/Arts-Awards/index.htm>> [accessed 28 March 2011]

'What does memorialising an account mean?', *Facebook FAQ*, <<http://www.facebook.com/help/?page=842>> [accessed 11 November 2010]

Zachary, Matthew, 'I'm Too Young For This Homepage', *I'm Too Young for This*, <<http://www.i2y.com>> [accessed 5 November 2009]

Zimmer, 'On Language: Wellness', *The New York Times*, 16 April 2010, <<http://www.nytimes.com/2010/04/18/magazine/18FOB-onlanguage-t.html?pagewanted=all>> [accessed 13 February 2012]

